Out-of-pocket Health Expenditure in Nepal

A case study on the implications of experiencing catastrophic health expenditure following acute medical need

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Abstract

Medical care in Nepal is largely financed by the individual, and although insurance programs and subsidies exist, they are limited in coverage, amount of assistance provided, and level of enrollment. Medical needs that extend beyond basic health services, specifically following acute injury can lead to financial difficulties that may jeopardize the ability to maintain basic needs and can push people into cycles of poverty. Costs for transportation, food, and itemized hospital charges can quickly deplete financial resources and require additional strategies to finance care, often through sale of land, loans, and forgoing of children's educations. The aim of this study is to both understand strategies that are devised and utilized to finance healthcare following acute medical need and the implications of such strategies. To do so, a qualitative study was conducted in urban and rural Nepal among 10 individuals who experienced acute medical need and consequential high rate of healthcare-related spending. The theoretical framework that guided the study was based on theories of trust, including how trust is generated and exchanged, as well as theory on the male breadwinner, in order to conceptualize the role of men in Nepali society. Finally, theories on social capital, including its significance in enabling relationships between individuals within families and exchanges with members of patients' local communities were utilized. Results indicate that patients often travel to multiple healthcare facilities before adequate diagnoses are given that address their medical need, leading to significant financial expense, impact on land ownership and land as mechanism for income-generation, disruption to livelihood strategies and children's educations, and inability to travel abroad as remittance workers. Findings have implications on healthcare-related financing and service care delivery in Nepal.

Keywords: Nepal, healthcare, catastrophic health expenditure, out of pocket expenditure, social capital, identity

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List of abbreviations

BHS – Basic Health Services

CHE – Catastrophic Health Expenditure

MFS – Minor Field Studies Programme

NHEDF – Nepal Healthcare Equipment Development Foundation

OOP – Out of pocket

OOPE – Out of pocket expenditure

SIDA – Swedish International Development Cooperation Agency

1. Introduction

On April 25, 2015, Ramesh was working as a trekking guide in the Langtang Valley of northern Nepal when a landslide swept through the area, triggered by a 7.8 magnitude earthquake, the largest to hit Nepal since 1934 (Okamura et al., 2015). The disaster, along with 200 subsequent aftershocks stunted the nation, killing an estimated 9,000, injuring nearly 22,000 (Okamura et al., 2015) and decimating thousands of homes, schools, and hospitals. Ramesh was lucky to be alive, as many others who were in the valley that day lost their lives. Miraculously, he suffered only a minor cut to his leg and waited four days to be airlifted to a nearby hospital where his wounds were stitched up and medicines prescribed before he returned to his home village, now in ruins.

A few weeks later Ramesh started to become weak and feverish. Eventually, he couldn't eat as his jaw had locked up, so he and his father walked three hours to catch a bus that would take them back to the hospital. He was once again given medicines and sent home, told to return a week later when bloodwork results came back. Upon returning home, his father wasn't able to give him the medicines that he'd been prescribed because he couldn't open his mouth. Traveling again to the hospital, the fifth they'd visit, they learned of the source of his problems; Ramesh had contracted a tetanus infection. His father quickly gathered the 28,000 rupees (250 USD) needed for a shot to counteract the infection, but Ramesh became worse with each passing day. He continued on a journey to improve the health of his son, travelling to three additional facilities and accumulating significant financial burden along the way. Ramesh's condition deteriorated and he was placed on a ventilator for 50 days, until he eventually lost consciousness after the ventilator broke down and a nurse administered oxygen by hand. Lack of oxygen contributed to brain damage, and Ramesh eventually became paralyzed. The possibility of a tetanus infection hadn't been considered by healthcare providers during earlier visits.

In the years before the landslide, Ramesh's father and mother had used their land to grow crops for their own subsistence and to sell at the market, a 1.5 hour walk away. Ramesh's father explained how some years before, a monkey infestation had bothered temple-goers in Kathmandu to the point that the government rounded the monkeys up and released them in their home village in an effort to rid them from the city. The land that they'd used to grow crops was now barren, as the monkeys quickly consume most of what is grown. This had a devastating effect on Ramesh's family over the years, as the land that they once depended on to support their livelihoods was no longer of any use, and the value driven down to the point that they wouldn't be able to sell it to finance Ramesh's care via loans from other villagers, land used as collateral. Without their sons working as trekking guides to support the family, and without land to grow crops, their financial situation became extremely troublesome, and the likelihood of being able to repay their loans grim. His father has since lived at the NGO in Kathmandu, away from his home village where the family home had been destroyed. To this day, the family sleeps in a room above where they keep their buffalo while a new home is built. I had the opportunity to travel with Ramesh's father back to his home village for the first time since he left three and a half years before, a truly sobering experience and one that I will never forget.

Ramesh's story reflects the experiences of many that I interviewed for this research study; a repeating narrative where an individual sustains an acute injury from an accident and then embarks on a long journey towards receiving a diagnosis that properly addresses their medical need. The ability to continue devising financing strategies as part of their ongoing care cycle then dictates their chances of receiving treatment and recovering from their health complications.

The following research study, based on patient and caretaker accounts, aims to understand patient experiences with the Nepali healthcare system following acute injury, including what strategies were devised to finance care, how livelihoods are maintained, and what effects such a journey can have on one's ability to fulfil the duties and responsibilities that are connected to their role held in their family. Further, the study seeks to bring awareness and understanding to the challenges present in the Nepali healthcare sector, as well as implications that such challenges have on the livelihoods and social standing of individuals and their families.

1.1 Research purpose & aims

The following research study sought to explore the experiences of individuals and families who have interacted with the Nepali healthcare system and faced catastrophic health expenditure following acute medical need. Catastrophic health expenditure (CHE, hereafter), is health expenditure that exceeds a 10% threshold of a household's total expenditure in a given month (Saito, et al., 2014: 761). Processes of trust generation and exchange are explored, including how trust is granted to medical providers, factors that enable such trust, and medically-motivated needs that enable trust-based interactions. Further, experiences on the impact that injury and financial strain had on individuals are explored, including aspects of involvement and contribution. Putnam (1993) explains such factors as essential components of trust that form 'social capital', a theoretical concept that is explored in detail and which the research study is largely grounded in. Further, the study explored impacts of CHE on livelihood strategies, including subsistence-based activities, and future opportunities.

1.2 Research question

The research study asked:

> *What strategies are generated and utilized to finance healthcare following acute medical need, how can they be understood, and what are their implications?*

The following study is interested in exploring the stated research question through concepts of individual and institutional trust as well as social capital created and exchanged between patients, their families and local communities. To do so, in-depth interviews were conducted among individuals and families who are either currently being provided or have previously received medical care through rehabilitation-focused, non-profit organization Nepal Healthcare Equipment Development Foundation (NHEDF, hereafter), as well as doctors working in the Nepali healthcare sector. NHEDF is funded by outside donors and provides on-site, cost-free medical treatment, rehabilitation, and housing to injured persons who previously received public or private care and were discharged due to inability to pay yet continued to experience outstanding medical need (NHEDF, n.d.). I volunteered as a marketing consultant for NHEDF in 2017 while on an internship period in Kathmandu. I would hear a reoccurring story about patients and their families who had sold their land to finance medical care, were left with outstanding need, yet inability to pay as their funds had been depleted. Hearing the difficult stories of patients and families, including the challenges they faced developed an interest to dig deeper and learn more about underlying factors common to their experiences.

1.2 Study significance

By identifying and exploring factors related to healthcare-related disparities experienced, future development planning can better target needs and work towards reducing the chances of citizens being pushed in cycles of poverty brought on by CHE following acute medical need. As out-of-pocket expenditure (OOPE, hereafter) is a major economic burden facing Nepalese citizens, the proposed research aimed to support the UN's Sustainable Development Goal 3 'Ensure healthy lives and promote wellbeing for all at all ages' and specifically target 3.8 'Achieving universal health coverage' (United Nations, n.d.) by bringing awareness and visibility. Financial risk protection from CHE is included within the target which highlights the inter-linkage between poverty and ill health and calls for larger investment in healthcare sectors (United Nations, n.d.). Identifying factors leading to CHE and its potential implications could work to make progress towards achieving these goals by connecting abstract scenarios found in the goals with empirical situations witnessed in Nepal.

1.3 Delimitations

The research study aimed to explore different strategies that patients devised to finance medical care and the implications of health expenditure on livelihoods. However, as data was collected through personal accounts of patients who received rehabilitation care through one single NGO, study findings may not be generalized to the experiences of all who seek out care. Further, it ought to be noted that while healthcare spending and its financial implications are of focus in this research, many factors contribute to individual and family financial situations that are outside of the scope of this study, yet likely of relevance.

1.4 Thesis disposition

The thesis is structured as follows: following second section provides a background of the Nepali healthcare sector, economic overview of Nepal, and significance of healthcare spending on livelihoods. The third section provides an overview of previous research on determinants and rate of catastrophic health expenditure, institution-based trust, and role of male breadwinners as providers in Nepali households. The fourth section presents the theoretical framework of the research, based on theories of trust, social capital, male breadwinner, and social role/obligation. The fifth section explains methodology, data collection, ethical considerations and limitations. The sixth section presents an analysis of study findings, structured by different stages of patient care cycles, and grounded in the theoretical framework. The final section offers a concluding discussion, highlighting implications of findings and possible areas for future research.

2. Background

The healthcare sector of Nepal is the focus of this research, as many factors impact patient experience in both accessing and financing care, including geographical placement, modes of income-generation, and personal networks. As of 2017, nearly 81% of Nepal's population of 29.3 million lived in rural areas (Data.worldbank.org, 2019). Of total labor force, 73.9% were employed in the agricultural sector and 6.6% in manufacturing (Nepal Labour Market Update, 2017:2). As of 2015, GDP per capita stood at $732, a growth rate of less than 1% in the years 2000-2015, compared to GDP of $1,582 for neighboring India and $5,692 for the South Asia region. (Nepal Labour Market Update, 2017:1) As of 2010/11, 25.2% of the population was noted to be in poverty (Nepal Labour Market Update, 2017:1)

Lack of wage-generating work opportunities in Nepal, prospect of higher earnings, and chronic political instability have push labor-aged men and women to seek employment abroad, representing roughly 8.3% of the total population, or 1.9 million citizens, a doubling over just a five-year period (Nepal Labour Market Update, 2017:3). Increasing wage flows from abroad has created a reliance on remittances for domestic growth (Nepal Labour Market Update, 2017:1), leading to a doubled share of GDP from 14.9% in 2005/6 to 21.1% in 2015/16. Further, estimates show that nearly 50% of Nepali families rely on financial help from relatives working abroad. (Nepal Labour Market Update, 2017:1)

The Nepali healthcare system is comprised of a mix of heath posts, primary health centers, and hospitals, and as of 2012 offered an average of three hospital beds per 10,000 population (Global Health Observatory, 2019). Health or sub-health posts provides basic health services of preventative, promotive and curative services in rural areas; each post representing on average of five village development communities (Kullabs.com, 2019). Primary health centers offer more in-depth medical services compared to health posts, but are less prevalent, with a total of 180 centers distributed across the country (Kullabs.com, 2019). Hospitals are present at district levels and include general, specialized, and teaching hospitals; ranging in type of care offered and number of beds. Compared to village posts and health centers, hospitals offer more reliable and well-equipped health services as well as more advanced equipment (Kullabs.com), but are geographically concentrated to urban areas. While healthcare facilities are in abundance, access differs greatly between urban and rural populations. As of 2010/11, 41% of rural households, which represent a significant majority of the population, did not have easy access to a health post or sub-health post, and nearly 80% were more than 30 mins away from a public hospital (Government of Nepal, 2011). Events triggering the need for emergency care often require individuals to travel to Kathmandu where thorough care is available but where costs for transportation and subsequent loss of income can have significant financial impact even before receiving the medical care needed (Mishra, et. al., 2015).

Out of pocket healthcare expenditure or costs paid by an individual for medical care without any supplemental assistance is the primary means of financing healthcare in Nepal. Such expenditure is stated to be the major economic burden facing households in the country and disproportionately affects rural communities (Ghimire, et. al., 2018; Government of Nepal, 2016). Such severe financial costs can lead to CHE, jeopardizing the ability to maintain basic needs, and can push individuals and families into cycles of poverty and ill health. In such cases, livelihoods become disrupted, including ability to work and generate income, as well as participation and contribution to family and social communities (Mohanty, et. al., 2017).

In presenting the Nepal Health Sector Strategy 2015-20, the Nepalese government has committed to establishing universal health care by year 2030, stating that access to basic health services (BHS), free of cost and the right to healthy living as fundamental human rights (Government of Nepal, 2016). Despite the ambitious goals, the current medical system lacks financial protections, is majority privatized and facilities providing a broad range of service are concentrated to urban areas. Collective risk-pooling insurance schemes which could assist in financing medical needs extending beyond BHS are minimal, generate low enrollment and low retention of members (World Health Organization, 2010). OOPE made up nearly 60% of total national health expenditure in 2015 (Government of Nepal, 2016), and higher for private care, representing 81% of total expenditure (Mishra, et. al., 2015). While public subsidies are present, they are largely targeted towards BHS, minimal in terms of services covered and limited in terms of the total amount of financial assistance they provide (Mishra, et. al., 2015). Making steps towards achieving long term goals, the Government of Nepal began rolling out and diffusing the Social Health Security Program in 2017, a comprehensive social contributory scheme with objectives of ensuring access to quality health service, protection from financial hardship and reduction out of pocket payments (Government of Nepal, 2017). Although the program signals positive developments in healthcare coverage, facilities accepting the scheme, types of services covered, amount of financial coverage, and level of enrollment are limited.

The presence of privatized care has greatly expanded in Nepal along with political and economic development in recent years. Private health facilities increased two-fold between 2007-2015 and accounted for 70% of total health expenditure in 2015 of which 81% of payments were made out of pocket (Mishra et. al., 2015). When medical needs extend beyond BHS or when public facility capacity is exhausted, individuals may turn to private services where care may be received more quickly and at a perceived higher quality, but where prices can be significantly higher, lack regulation and government oversight (Mishra, et. al., 2015).

Acute injury of a male head of household can result in long-term disability, which has many implications on the Nepali household, specifically on livelihood strategies, as males are the primary earners in their families as well as rights-holders related to land and economic activities (Pokharel, 1970:78). Individuals face difficult decisions in financing medical care following injury, from taking out loans from family, friends, or local village communities with added interest, to selling land assets or compromising children's educations (Ghimire, et. al., 2018). Acquiring large debt loads and depleting family financial resources can lead to cycles of poverty that have implications on the ability for the household to function as previously, as caretaker responsibilities may shift, financial security is threatened, and standing with local community members may become strained due to debts owed and difficulty to repay.

3. Previous research

3.1 Determinants and rate of catastrophic health expenditure in Nepal

Previous studies have explored both the rate and determinants of CHE in Nepal. Ghimire et. al. (2018) explored the cumulative incidence, distribution and determinants of catastrophic health expenditure based on a 2018 living standards survey, which provided a nationally representative view of CHE across Nepal's three main north-to-south geographical belts of mountain, hill and Terai-plain regions, as well as composition of literacy and economic status (Ghimire, et. al., 2018:4). The study reported an average monthly household expenditure was 30,000 NPR (414 USD) while monthly OOPE on healthcare was around 4%, or 1187 NPR (16.4 USD).

The study determined that of the households surveyed, 75% reported illness, of which 10.3% were associated with spending that led to CHE, of which the highest proportion was associated with acute illness and injuries versus chronic illness. Poorer households, household demography, urban location, female head of household, chronic illness and increased illness episodes were all positively associated with CHE (Ghimire, et. al., 2018:4). Further, CHE was disproportionately distributed across regions and attributed to household capacity to pay, meaning that CHE was concentrated to lower income households in the far west and mid-west regions of Nepal at greater risk of CHE due to lower economic status and compounded by lower rates of education and literacy, noted to potentially impact how cautious individuals and their families were in relation to their health-related behavior (Ghimire, et. al., 2018:8).

Half of reported episodes of CHE were associated with households that reported a double burden of illness, where more than one family member experienced some form of medical need, either chronic or acute. The study notes how the absence of comprehensive health insurance mechanisms, high morbidity, reliance on OOP financing for treatment and large share of poverty expose Nepalese households to increased risk of CHE. Further, noted implications on households that incur CHE include the need to sell assets, likelihood of compromising children's educations, and high risk of being pushed below the poverty line (Ghimire et. al., 2018:2).

However, studies on CHE have tended to be disease-specific and focused on urban areas, mainly the capital of Kathmandu (Ghimire et. al., 2018:2). Beyond the stated implications, little has been researched or reported on the implications of CHE on livelihood strategies, ability to fulfil family-based social roles, and impact on prospects for upward mobility.

3.2 Institutional-based trust between patients and healthcare service providers

The interaction between patient and the healthcare system as an institution is one between an individual who seeks out a public service from a healthcare facility as service provider. Institutions can be understood as “combined structures of rules, roles and human actors who generate activities” (Askvik, et. al, 2010:417) which play out through a combination of people, positions, procedures and processes (Askvik, et. al, 2010:417). While institutional-based trust can be granted to the parliament, central government, civil service, judiciary and police, performance-based trust of hospitals as a public institution is most relevant to the research study, as it explores trust based on individual assessment of the achievements and outputs of said institutions.

A study focused on the level of trust that Nepali have in public institutions found that performance-based trust, or trust based on popular performance appraisals of government institutions and policies (Askvik, et. al, 2010:417), was high for professional institutions such as school and hospitals, while lower for institutions of courts, civil service, the parliament and government (Askvik, et. al, 2010:430). While providing a basic assessment of trust in hospitals, the study was based on subjective indicators formed by each person interviewed, meaning that trust was constructed on a per-person basis rather than through consistent indicators such as satisfaction of interactions with healthcare providers or quality of services received. Further, the study was based on overall assessment of hospitals, and does not explore specific need states or types of services received that would dictate how trust may be formed and granted to said institutions.

A gap therefore exists between the level of trust placed in healthcare institutions and the specific variables that enable trust; for example, the nature and level of acuteness of medical need, whether the medical need was life-threatening and therefore time-sensitive, and differences noted between healthcare providers and facilities that may impact the level of trust. A combination of such indicators may dictate how reflexive a patient can be in determining whether or not to grant trust to the healthcare service providers before paying for and receiving services, or ability to differentiate between healthcare providers prior to selection of services. Finally, studies in general did not consider the implications of granting trust to healthcare service providers, forming a gap that the following research aimed to explore.

3.3 Role of provider in Nepali household: social and gender contract

Male as head of household

Pokharel (1970) discusses the roles and obligations of family members in Nepali households, which provides a clearer understanding of their significance. Individual roles form identities, and are based in part on deep-rooted social, cultural, political, economic and religious frameworks (Pokharel, 1970:65). Such frameworks structure traditional societies and form social contracts that establish role-based agreements between men and women (Gerhard, et. al., 2002:112). Males as "chiefs of the family" (Pokharel, 1970:78) stand as head of household, which carries a range of rights and responsibilities. Further, gender differentiation in traditional Nepali society establishes social order, specifically in terms of expectations of division of work and home responsibilities; men and masculinity linked to the public domain, which enable economic interactions with the outside world (Shakti, 1995), while women and femininity are linked to the private, their activities greatly focused within the household (Gerhard, et. al., 2002:109). However, differences have been noted between rural versus urban areas. Roles have also been noted to evolve with modernization and new forms of work carried out. Further, depending on the agricultural season, food scarcity may be more present, demanding that both men and women diversify their wage-seeking activities (Pokharel, 1970:74). The need to secure reliable labor has resulted in males migrating outside of Nepal as remittance workers, traveling the gulf states, where work is available (Pokharel, 1970:75).

Rights of the male

In terms of rights, Pokharel (1970) notes the power and authority that males have traditionally held as primary decision makers of the household, which enables them to keep their land in mortgage, obtain credit, and to both give and secure loans as men are seen as able to fulfil financial commitments (Pokharel, 1970:78). Women are noted to make minor decisions related to the household and children's daily activities, or are involved in consensus-based decisions, while men stand for larger decisions that impact the family and their relations with their community. Further, labor activities of males result in cash earnings while women's activities often generate earnings of resources that are used for day to day survival of the household (Pokharel 1970. p. 80).

Evolving gender contract

Rantalaiho (1998) discusses the concept of gender contract, which helps to frame the role of men and women in Nepali society. Gender contract is a modern interpretation of social contract anchored in cultural symbols and which establish a "pattern of implicit rules on mutual roles and responsibilities", which contribute to the realization of individual identities (Gerhard, et. al, 2002:116). The contract includes the rights and obligations that guide social relations between men and women, genders and generations, and between modes of social production and reproduction that organize societies (Rantalaiho, 1998:47). However, Rantalaiho (1998) goes further to explain that gender contracts are not static, but adapt in the face of changing circumstances and societal developments (Rantaliaho, 1998:116), resulting in a continual process of development in the nature and content of such agreements. For individuals whose positions in their families and societies are perforated due to altered physical states and abilities, social and gender contracts evolve to fit the changing circumstances.

While Pokharel (1970) provides a broad view of gender roles and divisions in Nepali society specifically, Nepal has changed significantly in the nearly 20 years since the article was written, as domestic migration has witnessed a flux of rural villagers relocate to cities, resulting in changes of modes of labor. Further, rate of outward migration of men moving abroad as remittance workers has also climbed significantly in recent years (Pokharel, 1970:75). Such advancements, amongst others, have led to a shift in female responsibility, and elevation of women as primary providers in the case that the male head of household dies or is incapacitated. This change seems to confirm Rantaliaho's (1998) conceptualization of an evolving gender contract in the face of changing social developments, personal circumstances, and resulting adaptations. Further, the country of Nepal is comprised of diverse cultural, class, and caste groups, amongst others, meaning that there is no one standard, homogenous constellation of gender roles and expectations connected to them. This suggests that the account of one caste or geographical group does not necessarily represent that of all others.

4. Theoretical framework

This section discusses the theoretical basis of the research. In order to explore the significance of trust as it relates to healthcare-related interactions, as well as its role in generating and exchanging social capital between members of a community, the theoretical framework draws upon conceptualizations of trust as a process, institution-based trust, male-breadwinner model, and social capital theory. The enablement of trust can be understood first from an institutional perspective, where trust is generated through a process of different stages that an individual goes through, which then rationalize trust being granted to another individual. In the following research, these stages are conceptualized through healthcare-related processes specifically. Further, the male breadwinner model is introduced in order to understand the significance of males as providers in Nepali households, as well as responsibilities and expectations connected to such a position. Developing the concept further, aspects of social capital are explored, including how trust enables exchanges of social capital within families and communities. A range of general theory and Nepali-specific context were utilized in an effort to stay close to the specific cultural context of Nepal. That said, there may be limitations to the applicability of theory due to an evolving Nepali society, as shifts in urban vs. rural placement have occurred at a high rate in recent years, which may have an effect on the roles and expectations of family members in light of changing modes of wage-generating activities and role-based obligations.

4.1 Trust: stages, types, and contribution to social capital

A key focus of the research is how trust between patient and medical providers is both enabled and granted. The need state of an individual requiring medical attention following a severe injury warrants a certain level of trust between the mentioned parties, as the former depends on the latter to provide a service that will lead to a hopeful outcome of improved health. Simmel, in Möllering (2001) illustrates trust as a process made up of three stages: expectation, interpretation and suspension. Expectation is the state at the end of the process, or the expected outcome; interpretation is the proof that provides good reason or rationale, which can be based on previous experiences or held knowledge, and; suspension is the mechanism of bracketing or omitting the unknowable (Möllering, 2001:403).

For those who seek out medical care, the three stages are suggested to play out as follows: following injury, the patient enters the first stage of expectation, where they seek adequate medical attention that will ideally address their medical need and aid them in reaching an improved state of recovery. Second, the patient moves into interpretation, where personally-held knowledge, information based on previous experiences, or the experiences of others provide good reason or proof that supports the acceptance of medical provider suggestions, and which rationalizes financing of care. Depending on the level of knowledge or experience, either held personally or transferred from others, the patient possesses a certain level of reflexivity, or the ability to reflect and ideate before agreeing to receive care. These factors, combined with the acute nature of the medical need, leads the patient to the next stage of the trust cycle, suspension. In this stage, the patient or caretaker as decision maker may bracket off or omit the unknowable, which may include the proper care that is actually needed, advantages or disadvantages of one provider recommendation over another, reasonability of pricing, etc. In the case of limited reflexivity, the patient may instead place trust in the recommendation of medical providers in a conscious or sub-conscious effort to reduce complexity of the high-risk situation.

Simmel's conceptualization of trust as a process (Möllering, 2001) is helpful in illustrating the process that patients may go through during their medical care journey, but lacks context as it relates to the specific factors involved in trust-generating processes. Therefore, Luhmann in Coveney et. al. (2008) is utilized, which offers an additional layer of perspective related to stages of interpretation and suspension, characterizing trust as a reducer of complexity (Coveney, et. al. 2008:180). In making any decision, a certain level of complexity is present that will dictate the weight that different alternatives carry, as well as different consequences that vary according to the significance of the decision. In the situation of acute medical need, complexity is high as a range of time-sensitive decisions need to be made, including type of care to be sought out, treatment alternatives, availability and choice of care facility, adequate medical competency of providers, and strategies to finance care. Trust as a reducer of complexity works through generalization, where trust that the individual places in the medical system acts as a substitute for inner certainty based on held knowledge. Instead, trust is placed in the medical service provider as a response to such complexity. While not eliminating it entirety, complexity is reduced, and trust is granted as a “functional alternative to rational prediction and decision-making” (Möllering, 2001:410).

Further, trust acts as a medium of interaction between modern society’s systems (institutions) and the representatives of those systems (medical providers); interactions shaped by facework commitments and faceless commitments (Coveney, et. al., 1991:181). Facework commitments depend on the perception of the patient’s care experience, including the medical provider’s level of professionalism, mannerisms, and other personality aspects that may have an effect on patient impressions and expectations. Faceless commitments are the perceived legitimacy, technical competence, and ability of the ‘expert system’ (Coveney, et. al., 1991:181). Rather than being based on facework commitments or the interactions between patients and medical providers on an interpersonal level, limited previous interactions with the medical sector combined with severity of medical need push decision-makers to depend on faceless commitments, that is, to trust medical providers as experts without question.

4.2 The male breadwinner

A key focus of my research was on the types of work activities that men were involved in prior to their injuries, and the implications that may result from a disruption on the ability to work as before. As detailed in section (3) on previous research, males as heads of Nepali households carry a range of responsibilities and expectations connected to their position in the family. The role that men play as providers focuses largely on economic activities that can support the household, leading them to engage in work activities outside of the home, while women often focus on household-based activities, agriculture and livestock. Social capital, of which a key element is trust, is largely a bi-product of the income-generating activities that men are involved in. A functional understanding of social capital is “networks and relationships existing in society, which are influenced by norms, values and rules, and held together through reciprocity and trust” (Hänninen, 2018:15; Parnwell, 2007). Social capital enables interactions and communication, builds up reputations, which in turn increases security within a network (Putnam, 1993). Men depend on the social capital that they possess, which enables interactions with others outside of the home, including the possibility to find work and ability to engage in economic exchanges between other males in the community, including possibility to acquire loans. A potential breakdown in the ability to conduct or fulfil labor-based responsibilities after injury or as the result of disability may lead to an erosion in the ability to generate such social capital, and is therefore a key focus of the research.

4.3 Social role and obligation

Theories related to social role and obligation grounded in social capital are offered by Fukuyama (1995); Edwards and Foley (1997); and Putnam (1993), and are utilized to understand social capital as enabling trust between patient and provider, family members, and between patients and members of a community. Further, these theoretical concepts are utilized to understand the meaning and significance of provider roles that individuals play in their families and communities, values attached to those roles, and the implications of a perforation or change to such roles due to injury, care cycle, and financial strategies devised for care.

The Social Capital Theory Framework put forth by Edwards and Foley (1997), builds upon Putnam's (1993) social capital theories grounded in trust and reciprocity. The theory's basis is rooted in cultural components of social capital which "add value to individuals who align or participate in a group as well as the value that is contributed to relationships and meaning generated" (Edwards, et. al, 1997). This perspective focuses on the position of individuals seen through the contributions that they make to society. Due to the study focus of patient and family livelihoods that are impacted by experiencing CHE throughout the care cycle, the theoretical framework aims to focus on the value that individuals feel they offer their community (family and non-family), and the possible implications of any disruption to such contributions. The social capital theory framework is further supported by an additional layer of social capital perspective by Fukuyama (1995), focused on trust, connectedness and social obligation. Specifically, the expectations that arise within a community based on trust and commonly shared norms (Fukuyama, 1995). Additionally, the perspective helps to understand the gendered nature of obligations. Through this perspective, the research study aimed to understand the roles that individuals feel they and/or their family members hold in their community, and held perceptions related to the obligations of said individuals in maintaining and supporting such obligations. Further, the theory helps to understand the interactions between patient, patient families and local communities in terms of the trust that is enabled by contributions and the implications that a breakdown in social role has on trust. Social capital theory as it relates to role specifically was used to guide research study aims, design, conducting of interviews, to assist in transcribing, and structure analysis of findings.

5. Methodology

5.1 General methodology

The research study was carried out in the form of instrumental case study, where individual cases studied can provide greater awareness and deeper understanding of particular issues. The case involved factors surrounding OOPE, eventual CHE, and impact on one's identified social role and obligation to their family/community. The study was based on qualitative data in order to identify the subjective perceptions of those impacted (patients and families) or those who have witnessed said experiences (healthcare providers). The theoretical framework aimed to support and build upon the researcher's awareness of issues in the field, and helped to purposely guide research questions and support further questions as they emerged during the study period. While acting as a guide for interviews, analysis and further discussion, the theoretical framework left room for the exploration of unexpected questions and considerations throughout the research process.

5.2 Research units and sampling

By interviewing different groups of individuals, the aim of the research was to gain awareness of a range of issues and perceptions as experienced at different stages and from different dimensions of stated issues. The quantity of interviews conducted worked towards establishing saturation (Punch, 2005) or the confirmation of insights and findings to emerge throughout interviews and analysis.

The research study was based on 12 in-depth interviews, comprised of:

- (6) individuals currently receiving care at NHEDF;
- (4) individual or family member of individual who received care and returned to home area following discharge from NHEDF;
- (2) doctors: 1 neurological surgeon; 1 spinal surgeon

A convenience sampling approach was used to locate individuals to be interviewed with guidance and assistance provided by NHEDF. I communicated the aims and ambitions of the study to my key informant, and trusted his recommendations of patients who fell within the study themes. By utilizing organization support, individuals most relevant to the research aims and goals were identified and sought out for interview. Interview guide development and interviews were conducted in collaboration with the organization to ensure study relevance and cultural sensitivity.

5.3 Collection of qualitative data

Throughout a nine-week study period, different sets of informants were interviewed across urban and rural locations in Nepal. An interview guide was first developed in English based on the study's theoretical framework, translated to Nepali and utilized by a hired translator during interviews. Interviews were conducted in Nepali through the assistance of a hired translator following four total hours of instruction where I as researcher presented research aims, theoretical framework, and the proposed interview guide in an attempt for the translator to understand study goals and ambitions. Interviews were semi-structured which allowed for additional insights and findings to spontaneously emerge, which ultimately supported a richer and more in-depth analysis (Punch, 2005).

Interviews were conducted primarily one-on-one with patients directly or with a parent if the patient in focus was a minor or diseased. A consent form was developed prior to the interview period, stating the complete voluntary nature of the interview, ability to end the interview at any time, that subject information would be de-identified, and that interviewees were in no way or form obligated to disclose any information that they did not feel comfortable sharing. Expressed verbal and written consent were received from the patient or family member via a signed consent form prior to audio-recording of conversations and can be found in the appendix portion of this paper (section 8). Interview transcriptions were thematically coded and analyzed by hand.

5.4 Ethical considerations

Healthcare-related experiences of interviewees are sensitive in nature, as individuals recounted difficult, painful experiences, both emotionally and physically. Further, interviewed patients were in a vulnerable state, offering intimate details about their health status, medical background, financial standing, and insecurities about the future due to their experiences. In an effort to be respectful and considerate, a consent form was presented to patients and included verbiage about the possibility to pause or end the interview at any time, for any reason. While interview guide was developed around key themes that I as researcher hoped to explore, questions were open-ended and allowed the interviewee to respond as they felt appropriate and to their personal emotional capacity. Further, patients and their family members named throughout the study have been given fictitious names in an effort to protect their identities and dignity.

5.5 Limitations

Analysis and discussion of interview data must be viewed in light of the following limitations: First, majority of those interviewed were men, meaning that accounts of women, including factors that may influence their quality of care and implications of their experiences may go unreported. Second, patients interviewed were from a convenience sample developed with guidance from the NGO in order to represent patient experiences closely aligned with study aims, meaning that certain patient experiences may have greater bearing on findings than those of non-interviewed individuals, which could be seen as a form of bias due to the intentional selection, and which would have added additional perspective relevant to the study. Third, a translator was hired to assist in translating/conceptualizing interview guide into Nepali, conduct interviews and transcribe interview audio. Due to differences in language between English and Nepali, there is possibility that information was lost in process, or that the intentions of the translator may have influenced the flow of interviews and information provided by interviewees. In an effort to work against this, I met with the translator on three occasions prior to the first pilot interview where I presented the interview guide, study ambitions, and sought out her perspective to ensure cultural relevance and smooth diffusion and of the study.

6. Analysis

Through analysis of interviews with patients, caretakers and medical providers, three primary themes emerged: (1) Initial injury and start of care cycle; (2) Strategies devised to finance care, and; (3) The pursuit of a suitable diagnosis and its implications, including sub-themes of (3.1) Implications of injury, financing strategies and depleted financial means resulting from care cycle; (3.2) Altered social standing and exchange of social capital, and; (3.3) Downward mobility. The interconnected themes depict a repeating narrative where an individual experiences some form of physical trauma from an accident, make attempts to locate a medical facility with adequate competency and services to address medical need, be successfully admitted, start a journey towards identifying an adequate and accurate diagnosis, develop financing strategies to fund care following diagnosis, and finally, face the prospect of navigating an unstable future due to previous income-generating activities no longer possible to carry out due to changes to physical conditions.

6.1 Initial injury and start of care cycle

Following the accident that resulted in acute injury, a patient's process of care and recovery begins, which I have termed 'care cycle', understood a series of processes that include the locating of a healthcare facility and seeking out of adequate healthcare provider and competency to treat the specific need. Figure 1 (Moroni, 2019), below, illustrates the care cycle.

<u>Illustration of patient care cycle</u>

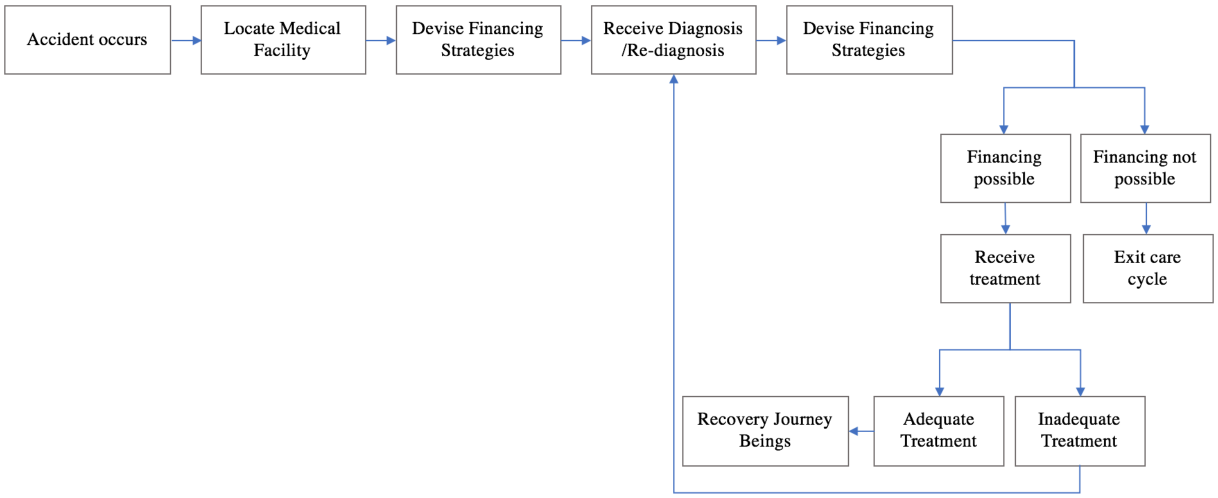

Figure 1: Patient care cycle by Matthew Moroni, 2019

Patients often communicated how after first arriving to a particular health facility, determined by proximity to their home or where the accident occurred, they were either first diagnosed and prescribed treatment, or instructed to continue on to another facility due to severity of need, lack of adequate competence in present facility, overcapacity, patient inability to pay, inability to determine new diagnosis and subsequent course of treatment after receiving their initial diagnosis and treatment. Movement from facility to facility did not seem to be done formally by referral or coordination between facility staff but rather patients moved by their own effort and financial means following provider instruction or recommendations of acquaintances. Finally, information about injured loved ones was often not communicated to relatives, leaving them to wonder about their health status. For Kamal, after an explosion due to a gas leak occurred in the family home while they were sleeping, he did not learn that three of his family members had died or where they were located until days after the accident:

> "*The three died in [hospital], but we hadn't received any information on them. We just got the news of their death and now I am carrying that sorrow with me*."

6.2 Strategies devised to finance care

In order to begin receiving medical attention, and as part of the care cycle, patients and their families embark on a journey of devising strategies to finance needed care and strategies to meet household and family needs back home.

Financing provided before services rendered

Patients explained how proof of financing needed to be provided up front before services would be provided. This led many to immediately exhaust whatever savings they had available to finance costs for transportation to facilities, and charges for in-take, bed, tests, scans, and itemized costs such as medicines, food, medical tools, and clothing for medical staff.

Even when utilizing savings, most patients had to resort to securing additional finances in order to continue their care cycle, otherwise face risk of being discharged, which for some could lead to loss of life or permanent physical ailment. Many sold a piece of land, either the area where the family lived and worked on, or land that was meant to be inherited following the death of a parent but sold in advance. Others either first turned to loans or eventually sought them out, which were noted to be secured through other family members or local communities by offering land or assets as collateral:

> "*I sold the land that was in my ownership. I sold everything I had, even some of her [his wife's] jewelry, the goats, everything. That didn't help much.*" - Gopal
>
> "*I started selling the land I had and then when I was in Kathmandu, we used up all the money. I was getting treatments for 4 years and that money did not even suffice for a year.*" – Gopal

If financing strategies could not be devised, patients then exit the care cycle, meaning that care ends while outstanding medical need persists.

Government assistance

One caregiver noted that as his son had been injured as a result of the earthquakes, the government was supposed to cover costs for care. However, when explaining this to hospital staff, he was told he would need to pay up front, later learning that the scheme was only available at few hospitals located in the Kathmandu Valley. After a long process of trying to secure the waiver from the government, he received a back payment of aid of 50,000, while noting that he was to receive 300,000. In total, he noted accumulating 1,600,000 in loans (14,344 USD). This experience was repeated by another man who had been injured as a result of previous Maoist uprising, yet he did not receive expected compensation.

Strategies to maintain household needs

When patients or their caretakers served as the primary source of income in the family, family members back home took over responsibilities to take care of children and sought out other forms of labor to generate income in the absence of a primary earner. Some patients' children's educations were paused so that children could work to generate income or to assist the mother in taking care of other siblings in the absence of a male provider.

6.3 The pursuit of a suitable diagnosis and its implications

The next phase of a patient's care cycle is the pursuit of a diagnosis that adequately and properly meets their specific medical need, which was noted to have a range of implications, discussed below. This phase was for many a long-term pursuit marked by inadequate or in some cases incorrect diagnoses that led to further health complications.

Locating facilities & seeking a diagnosis: a recurring cycle

Many sought out care at the facility closest to their home, ranging in level and quality of services provided. In some cases, patients were not given a choice of care options but instead complied with the recommendations of doctors, noting them as experts:

> *"I told the doctors that I don't know these things, we have put him in your hands so do what you have to do. We don't know as it is all in the doctors' hands." – Kumar, father of Ramesh*

Patients noted not having agency over their own care, which led to questions and uncertainty around medical treatment received:

> "*They made me do x-rays, I did not know what had happened inside. After the x-ray, they did not even tell me about the metal screw that was put inside me. I had no idea.*" - Mohan, following rod put in back, surgery on legs

Additional care was often sought out on the patient's own initiative after a period of no significant improvements observed or when further complications were experienced in the period following surgery. Patients and their families then continue down a long path of identifying a proper diagnosis, while making significant financial investment and accumulating additional debt to finance new care as prescribed.

Most had visited four or more facilities before an accurate diagnosis was given. Kumar, a man in old age and father to Ramesh explained how his son was working as a trekking guide when he was injured during a landslide triggered by the earthquakes in 2015. At the first facility, his son's minor wounds were stitched up and pain medications prescribed, but the severity of the cut and risks associated with it were not properly addressed, and the medicine prescribed could not be given to his son upon returning home as his jaw was locked. It wasn't until the fifth facility and significant medical expenses paid that a diagnosis of tetanus infection was given, indicating that earlier treatment had missed identifying the risks that led to the infection. By the time the infection was determined, his son was paralyzed and in need of a respirator.

Diagnoses that failed to address the true medical need of patients were cited to be a result of lack of protocol and inconsistency in types and depth of medical examinations prescribed, such as x-rays that looked at outward bone health versus MRIs or CT scans that could identify internal views of bones and organs. In some cases, treatment and/or surgery failed to identify their greater medical need, resulting in increased severity of their original need. Referring to bone tumor that was not identified as x-rays were done rather than bone scans:

> "*X-rays were done, it looked normal, but if proper diagnosis is not done by the doctors, it won't be known*." - Gopal

While this cycle of multiple diagnoses was experienced by most patients interviewed, there seemed to be acceptance of initial and additional diagnoses with little pushback with each further phase of care. Patients explained how they trusted doctors as experts, as they possessed the medical knowledge that patients themselves did not have. Further, due to the seriousness and time-sensitive nature of medical attention needed, and money-sensitive nature of experiences, patients seemed to place trust in medical providers and the course of treatment prescribed, even when earlier diagnoses and prescribed treatment failed to address their needs. Trust seemed to be further enabled by the high-risk nature of patient situations, as medical providers possessed the ability to prescribe a course of treatment that may eventually lead to an improved outcome, leading to patient and caregiver compliance:

> "*I told the doctors that I don't know these things, we have put him in your hands so do what you have to do. We don't know as it is all in the doctors' hands*." – Kumar, father of Ramesh

Following initial treatment, often prescription of pain medications, patients noted that they or their loved ones were instructed to seek out care at other facilities where more advanced or broader range of services care could be sought out. However, accounts revealed that there was no guarantee that receiving hospitals had bed vacancy, or that staff would in fact be available to meet patient needs. Patients then needed to wait until a provider was available, incurring costs for bed charge and ongoing care throughout, and often transitioned to other facilities on their own effort in the hope of receiving care more quickly.

Upon arriving at further facilities, patients noted experiencing long wait times in order to see a provider, of which maybe only one would be available in the entire hospital that could address their particular need. Others waited long periods for receipt of care following diagnosis. While in a waiting period, patients had to continue financing costs for housing and food despite issues being related to administration and patient capacity of hospitals. Hari and son Saila waited 24 days following an appendicitis diagnosis to undergo surgery, which contributed to the formation of an abbess. Further, his original medical need of a broken leg was not properly addressed:

> "*In all these hospitals [names 8 different facilities visited], now we are here. We have been to so many places but he still can't walk.*" – Hari, father to Saila

When medical providers recommended patient transfer to other facilities, movement was done without inter-hospital coordination or guarantee that the patient would be admitted despite acute nature of need. Kumar and his son were threatened and forcefully discharged when no improvements to his condition were seen:

> "*There were many empty beds at the hospital. Our of 100 beds, only 5-6 were occupied so I asked how having my son would harm anything. They said that other patients will come and they have to take care of others also, and insisted on discharging him. I did not ask for free medicines. I just asked for a bed for an earthquake victim. They insisted on us leaving every single day. The hospital warned us to empty the bed within a week.*"

Another patient's mother echoed similar experiences after the family could no longer pay for care for her son following brain and head trauma:

> "*They put him in the ICU for seven days, then shifted him to the ward when we couldn't pay the money. Then the doctors also kept on telling us to leave because we did not have money.*"
> - Kumari

Likelihood and speed of being admitted to hospitals was noted to be dependent on personal connections:

> "*They said that it is difficult to get ICU in public hospitals, only those with some power can get it in Nepal*." - Kumar

Upon arrival at the 14th facility, Kumar and his son were admitted due to a personal connection from their home village:

> "*Then there was a villager's son who worked at Bir hospital and I shared about our situation with him and he helped admit my son to the Trauma Center and he also talked to the doctors there*." - Kumar

Compounding health problems

When patient medical needs were not adequately addressed in the first few facilities visited, on average, health problems increased in severity and even compounded into further problems. For one patient, the severity of his broken bones was not properly identified in the first two facilities where he was told he had only bone fractures. The patient explained how doctors conducted surgery to repair the fractures, but it wasn't until the third hospital visit following additional complications that a different doctor conducted a CT scan that identified a tumor in the bone. It was also determined that he did in fact have broken bones, not simply fractures, of which shards had spread throughout his body that threatened to damage his bladder and which contributed to a blood clot in his stomach.

Patients noted being discharged when their finances were depleted or in event of no further improvements in condition. This led to a sense of desperation, as many saw no other alternatives to seek out to better the condition of them or their loved ones. For Mohan, following injuries of broken bones, had been passed around to different hospitals after x-rays did not reveal what his problems were. He expressed that he did not want to repeat all the tests he had received before, only to possibly receive no diagnosis:

> *"We told them what they'd told us earlier, instead of making me do all the tests and telling me my bones are not broken. We had no other option but to leave there because*

> *they would not keep us. They said either go to [other hospital] or go home, they would not keep me there anymore."* - Mohan

When patients were unable to devise a strategy to finance further care they were in some cases discharged from the hospital where earlier care had been received:

> "*They put him in the ICE for 7 days then shifted him to the ward when we couldn't pay the money. Then the doctors also kept on telling us to leave because we did not have money*." - Kumari, mother of injured son

Hospital staff were even noted to speak harshly to patients and family members who were unable to pay:

> "*The sisters*[1] *would scold mother as we couldn't pay. Same in all hospitals. When we didn't have money, everyone treated in the same way. They are supposed to take care of the patient, but they would make mother do everything. She faced a lot of trouble*." - Kumari

Sense of desperation

The journey of receiving an adequate diagnosis led to a sense of desperation among patients, as they often paid such high costs yet were not assured that the care they received would in fact improve their situation:

> "*I asked the doctors how much more I would have to spend as I had already spent around 800,000 NPR (7,172 USD). I was angry because there were no results even after spending so much for 10 days. I had loans, and I just wanted to get cured soon*." - Rami

One patient felt that it would be better to cut off his leg than to risk further complications and additional costs for possible treatment:

> "*I told them to cut my leg off if needed because I couldn't take it anymore. What could I have done? I had a lot of tension even after the operation*." – Mohan

---

[1] Sister or 'didi' in Nepali culture is a reference to an older sister, auntie, or in this case, a nurse

Sense of desperation led another patient to attempt suicide:

> "*I did not know why I should keep on living. My wife said that I tried killing myself*." - Gopal

Little emphasis on rehabilitation and follow-up care

Patients expressed how physiotherapy and ongoing care were not emphasized by medical providers after surgery, leading to risk of paralysis or lifelong physical ailment. High costs were paid for surgeries and prescribed care, yet the success of such treatment was noted by surgeons interviewed to be contingent on follow-care in the months and years after care. Referring to loss of sensation in legs and feet after spinal surgery:

> Maya: *"I ended up like this because I didn't do physiotherapy, otherwise I would have gotten much better."*
>
> Interviewer: *"Had you received any such recommendations before (referring to physiotherapy)?"*
>
> Maya: *"No, nobody did."*

However, when physiotherapy was provided by the NGO, improvements in physical conditions were noted:

> "*My pain had reduced and physio helped a lot. I felt the power return in my legs. My legs were very weak. Now I can walk with the help of one crutch*." – Maya

Another patient, noting the importance and benefits of physiotherapy:

> "*My problems would not have been solved with just the surgery. The movement would not have come back and I wouldn't have been able to walk as I do now, had it not been for NHEDF's help. After receiving physiotherapy, the movement in my legs returned and the muscles in my leg got stronger*." - Gopal

6.3.1 Implications of injury, financing strategies and depleted financial means resulting from care cycle

Possibilities for improvement of health

Despite malpractice or less-than-adequate diagnoses, patients were expected to pay for services rendered throughout their care cycle, as well as for ongoing costs including bed charge, food, and medicines. Once a proper diagnosis was finally reached, costs for inadequate treatment that was already paid for and received, patients were not granted any sort of credit or refund for faulty services, but instead were expected to finance any additional care that was prescribed.

Once a proper diagnosis was given, costs to finance previous treatment lead to a scenario of depleted financial means where patients then needed to either devise new strategies for financing care or go without the prescribed treatment. This scenario was revealed through the experiences of Hari and son Saila. After experiencing bone pain and later a broken leg after a fall, no real related diagnosis was given to Saila. Later, after moving on to additional facilities and following four MRIs at the insistence of his father, it was determined at the fifth facility by an orthopedic specialist that Sila had a tumor growing in the bone, which contributed to his weakened state that led to the fall. As the diagnosis came so late into his care journey, the family had already spent 680,000 NPR (6,100 USD). Financing was acquired through loans, which did not allow them to complete the six rounds of chemotherapy needed, as care would require an additional 700,000-800,000 NPR (6,275 – 7,172 USD). Another patient had received 16 operations in the span of 50 months after cancer was discovered following location of a tumor, although first two hospital visits did not identify the problem.

In the case of Kumari, costs for cranial and spinal surgeries for her son were raised through a combination of donations and loans, the surgeries were carried out, but costs for a respirator following surgery that would stabilize her son could not be paid for due to depleted finances. He was not placed on a respirator and died hours later:

> "*They asked me to take him to a private hospital because he had to be kept in ventilation. I didn't have the money. I thought, we will stay there. Whatever happens, happens. I massaged his feed and stayed there all night. At 2:20 he passed away.*" - Kumari

Disruption to income-generating activities

The majority of those interviewed were men, all of which had been working labor jobs as a means of generating income to support their families. Due to the acute nature of their injuries and physical ailments experienced as a result of accidents, most men were unable to return to labor jobs as previously worked, including construction work, as remittance workers in foreign countries, or raising of livestock. Himal, young father of two and main provider for his family explained:

> "*I can't carry heavy loans now, and that used to pay more as the work involved hard labor. Now I just work with my hands packaging foods*." - Himal

Inability to work lead to immediate loss of income and low likelihood of earning similar levels of income as previously due to changed physical state. This had a direct effect on livelihood strategies, forcing families to change course and devise new livelihood strategies to meet their family's financial and household-related needs. After Kumari's son died, her daughter returned from the Gulf to support the family. As the children were the main income sources, the family no longer had a source of financial stability, leading to difficulty in managing the household.

> "*Everyone's just staying home. We have no income source. When she was working abroad it helped but she's also here now. It's difficult to run the household now*." - Kumari

Kumar and his family depended on their sons' work as trekking guides to support the family, income flow that stopped due to one son becoming paralyzed following tetanus infection, while the other son moved home to assist the mother. Agricultural work that had previously provided income was no longer possible due to land areas becoming barren due to a monkey infestation.

High debt loads, unknown likelihood of repayment

Financing healthcare costs led to all patients acquiring severe debt loads. Faced with the prospect of not being able to return to work activities that would allow similar levels of income as before, patients expressed feelings of confusion and insecurity about how to repay borrowed funds.

Loans via loans

For some, additional loans were sought out from family and community members in order to pay interest on previously-obtained loans, leading to a cycle of owing money to many different people:

> Kumar: "*I arrange money somehow for those who have asked it back. I understand that it will be difficult for them too, living in the village. To those who are really in need, I borrow from others and pay back*."
>
> Interviewer: "*How do you manage to pay the interest?*"
>
> Kumar: "*Borrow from other people*."

Role of land and implications of loss on livelihoods, income generation, and collateral

Land was stated to be a key mechanism for financing care, often sold in order to quickly generate money to finance accumulating costs, although rarely meeting needs and demanding the devising of additional financing strategies. Through patient accounts, the significant role of land became clear. Land was a mechanism for income generation through agricultural or livestock activities and the area where the family home was located.

Livelihoods

Family homes in Nepali culture house multiple generations of family members. When the land where homes are located was sold, families were forced to disperse and relocate to other family members' homes. Patients explained that following their care, there was great insecurity around whether or not family members would be able to reunite as one household, as the ability to finance the purchase of new land and a new home weren't possible due to their financial difficulties.

Income generation

The sale of land lead to a depletion of space to continue agricultural activities and raising of livestock that provided subsistence and, in some cases, mechanism for generating income through the sale of crops and livestock. In the case of Kumar, knowledge of when and how to grow certain crops went unutilized as he was no longer home to provide, but was based in Kathmandu seeking care for his paralyzed son:

> "*We can't do it because of the monkeys and also because my son doesn't have much idea about which vegetables to plant in which season. He doesn't have much idea and he can't save much either*." – Kumar

Their problem was further compounded by the fact that their family home was destroyed by the earthquake that led to his son's injuries, forcing the family to instead sleep in a room above the area where they house livestock. Further, their land became barren due to a monkey infestation after the government released monkeys into their village in an effort to remove them from temple areas in Kathmandu:

> "*We don't get to farm anything because of the monkeys. They have adversely affected the farming there. Otherwise, we had very good crops*." - Kumar

This reality severely hampers the likelihood of becoming economically stable, as land cannot be sold due to its depreciated value in light of inability to grow crops:

> "*Our situation is very critical now. We are in debt and we have to pay it eventually. If there weren't any monkeys, we could sell land and clear the debts, but now even if we sell half of our land, we don't be able to pay the loan. There isn't anyone to buy the land. It can't be bought for farming because of monkeys. Also, there isn't anyone to work in the field. When people started realizing that farming couldn't sustain them and their family, many went abroad*." – Kumar

Collateral

For those who owned land but had not yet sold it, land was stated to be a form of collateral that could be used in order to obtain initial or further loans from community members or women's labor collectives. Land that was used as collateral or sold directly was either land that families lived on personally, was a loaned section of a family member's land, or was land that would have otherwise been inherited following the death of a parent living at the time of interview.

If land was sold to generate cash, patients were left without land as mechanism to obtain additional finances. It was communicated that owning a piece of land served as a mechanism for enabling a sense of trust between patient and potential loan giver. If the individual loaning money knows that the promise of land sits behind the agreement, they can have confidence in lending money. Where land or other significant assets are not available, the likelihood of obtaining additional loans was unlikely. As a result of land being sold, possibilities for income generation were reduced, indicating depleted levels of social capital that would enable other livelihood strategies through the help and aid of others.

> "*If I had any land with me then they would be more comfortable to give me the money*."
> - Mohan

> "*If it was in a bank, I would have to keep something as collateral. To sell the land too, nobody is going to buy it, because of the monkeys. I have to pay back the loan. I will be sinned if I don't pay it back. I have to pay back my son-in-law for constructing the house too. He also has family, kids, he needs money. He must have got loans from others too*." -
> - Kumar

Inability to jump-start future work prospects or diversify modes of labor

Many who were interviewed communicated how as they were or would be unable to return to labor work, and would need to instead turn to other types of work to generate income, such as side businesses, selling of handmade products, and raising of livestock. A common sentiment shared was one of lacking capital to generate capital, as money is needed up front to finance new types of work, including purchase of land, buildings, and materials. As work prospects were limited and debt loads severe among those interviewed, the likelihood of being able to either save money or obtain additional loans were unlikely. This reality had severe negative psychological effect on men, leading to a depleted sense of belonging and inability to devise new strategies to securely move forward:

> "*If there is heaven and hell, my life now is like hell. My plans for the future have been ruined. I couldn't fulfill any of it. My life is broken like glass. In such a situation, I want to work for my child. That's it. I had plans for my child and my family, but I couldn't fulfill any of it*." - Kamal

The sentiment was further communicated through Mohan's account:

> "*We need money to earn money. When I was working, I was sending money home every month. We did not have financial problems. But now we have lost everything and I don't know if we can go back to that state. Even if we could, we don't have anything to start with*." - Mohan

6.3.2 Altered social standing and exchange of social capital

Interactions and social standing between patients, their families, and local village communities were enabled by social capital which was communicated to be generated by work activities that were conducted prior to the patient's accident. The ability to continue generating and exchanging social capital following injury and patient care cycles were impacted by their physical abilities post-care, now altered due to their injuries and long-term physical ailments. Changes in generation and exchange of social capital led to many noted effects, most relevant being a sense of belonging, feeling of fear due to inability to repay loans, lowered perception of the patient by their community and the ability to obtain additional loans from other villagers to finance future care.

Inability to return to labor work leads to others needing to step into provider role

As the majority of those interviewed were the primary earner of their family, inability to return to labor work led to others in the family needing to step in to fulfill the role, including wives who turned to labor work, children who paused their education in order to seek out work, and elder parents who stepped back from retirement status to return to labor work in order to meet the needs of their family. Further, a transfer of main provider puts strain on others and leads to psychological distress:

> *"I am the one who earns for the family. I am the only son. The responsibility of the house is on me. My parents are old now, yet they are still working. In a time when I should be taking care of them, I am living here, disabled, so what can I do in the future? Everyone is now struggling. I worry about this."* – Nimai

Maya, who cared for her younger siblings after the father left the family and the mother passed away, explained her concerns about the well-being of her siblings:

> *"Meanwhile, my brother also got ill and people used to say things about the state that I was in, and now my brother also. I cried a lot during that time. I fainted after the bruises got worse."* - Maya

Others take on new roles – evolving breadwinner status

Elderly parents of patients, wives and children were all noted to take over as providers in some sense, turning to labor work despite old age, depleted physical condition, or limited capacity to carry out labor-intensive tasks. In referring to his wife, Kumar expressed:

> "*She does a little, she is not strong like before. She is stressed and has gotten weak. She is also getting old.*" - Kumar

Emotional impact of altered perception of identity and inability to fulfil role

Inability to fulfill a family-based role as previous led to a feeling of confusion about one's sense of belonging. If they were unable to fulfill the duties of being a father, husband, or older sibling as primary caregiver, patients expressed a feeling of being lost, unsure about how they would proceed. For one man, the inability to work and provide for their family as before led to an insecurity of not knowing where he belongs and questioning whether it would have been better to die:

> *"I don't know what to do, how to go ahead with life. More than anything I am worried about paying back the loans. I feel stuck between working hard or continuing to live. I don't know where I belong. I neither belong here nor there, hanging in between. Had I died, it would've been much easier, especially for them [referring to his wife and children]. The three of them could have lived happily, thinking that death is inevitable. Instead, living a disabled life like this is really difficult."* - Mohan

Deliberation between receiving care or providing for family

Patients who were unable to fulfill their caretaker roles as before expressed a scenario where they had to decide between seeking out the care that was needed following their accident or taking care of their loved ones, as being away from home for treatment and/or allocating finances to their own care might lead to their children or siblings not being provided for.

> "*I still feel that I will get better with treatment. I would go by myself but I have my younger sister, there is nobody to even cook food and feed her. …*
> *Regardless of my pain, I got them to continue their education instead of investing on my medical care.*" - Maya

A feeling of shame was expressed as resulting from one's personal health struggles which impacted the lives and futures of loved ones. Referring to sons who had to stop their education because of their father's healthcare costs:

> "*I feel like I have ruined their lives. Because of one person, so many lives have been ruined. Had I died instead, at least they could have studied, and we wouldn't have as much loan.*" - Mohan

The implications of their situations led some to question whether it would be better to die than to cause others to continue to suffer due to depleting financial situation and physical demands due to deteriorated condition:

> "*I thought we should just go back home instead of troubling others. If I die, I'll die there, if I survive then fine. … I feel tense and worried about the future. I hope nobody has to suffer like me.*" - Mohan

Psychological toll resulting from perceived inability to pay loans

Patients and caretakers communicated that the stress to repay loans was heavy on their minds and gave them a severe sense of insecurity about the future, as the prospects of working to a level that would generate income to repay loans was increasingly challenging:

> "*In that stage, I only had Rs. 30,000 (279 USD) after selling the goats. I needed at least 200,000-250,000 (1,800-2,250 USD) for the operation. I did not know how to get that money so I went into depression. We still have to pay the loans back. At present, they sometimes come to our house also and we can feel the pressure. I feel the pressure of those loans.*"
> - Gopal

Stress to repay loans extended to other family members, who also suffered psychologically, and in one case, led to physical violence of a family member who assisted a patient financially:

> "*My brother in law would scold her for giving me money, and he'd say bad things. So, my younger sister and brother started working*." - Maya

Inability to repay loans led to community members seeking out the borrower's family, demanding repayment, creating a social imbalance and confusion about how to proceed forward due to lack of a source of income and inability to fulfill their commitment to pay back loans:

> "*After borrowing from someone, when we're not able to pay back in time they come to the house to ask for money. We don't have an income source so it feels bad. When they come home, and we don't pay them by the time we said we would then we are also in an awkward position. If we had some income source then we could have some kind of reassurance to pay back from that earning. But it's difficult because we have borrowed from different places*."
> – Sarita, daughter of Kumari

Financial strain was noted to creates imbalance between family members, leading to patients and caretakers withholding information from family members about their financial burden:

> "*The family at home does not know about the expenses incurring here. Lenders are also worried as we have no source of income*." - Hari

Another patient noted changes in how his family responded to him after he accrued such heavy financial burden:

> "*Everyone was angry. They wouldn't even receive my phone calls, they wouldn't even check on me. We fell apart."* - Gopal

Shankar noted how relations between he and his in-laws were strained after he was unable to continue working due to his physical ailments:

> "*My in-laws say things to my wife. They told her to divorce me*." - Shankar

Insecure social standing without male leader of household

The death of her son and the absence of a father led to an all-female household. Kumari's daughter explained how the community treated her family differently, which led to a feeling of insecurity of no male in the home:

> “*When the male in the family died, that’s obvious [to the community]. They think low of us. They speak lowly of us. They insult us. Not having a male in the family, it is bound to differ. A family without a male is difficult. Had there been a male then nobody could have harmed us. But now it’s just us females*.” Daughter of Kumari

Referring to treatment by villagers after her father left the family and mother passed away, which urged she and her siblings to move:

> “*The villagers also said bad things about us, and it didn’t feel right to keep living there*.” - Maya

One patient expressed the shame and oppression felt from community members when he was no longer able to support the family as before:

> “*When something happens to the bread-earner of the family, everyone oppresses the family. Some people even turned their phones off, blocked me from their phones.”* - Mohan

Another patient explained that others were superstitious of him after his injuries and diagnosis of cancer, fearing that they would be infected, which led to him distancing himself from the community after he was refused housing:

> “*Some people perceive cancer as a communicable disease. They say that people with cancer also have other diseases like hepatitis B and others. The concept is that one should not mingle much with such people and stay away. People and friends with whom I used to eat together now look down on me. Some people didn’t even rent out a room for us to live in after knowing about my situation.”* - Gopal

6.3.3 Downward mobility

Most patients were noted to be main provider of the family as the male bread winners of their households. Following care and rehabilitation, and due to their altered physical conditions, most were unable to return to similar labor activities as worked in the past, which had an effect on the mobility prospects of patients themselves, as well as their spouses, siblings and children.

Forgone education of children & psychological implications

A common theme to many of those interviewed was one of forgoing children's educations in order to utilize the funds paid for tuition fees to instead finance medical costs. This scenario was noted to be a major psychological strain among those interviewed, leading to a sense of guilt that their children may not advance to the level they might have had they continued to study. Many men noted that their primary motivation to continue struggling to recover or return to good health was their children, and the prospect of them returning to school again.

Possibility to work abroad as remittance workers, limited opportunities at home

Some of the men interviewed had previously worked as remittance workers in countries such as Malaysia, Kuwait and in the United Arab Emirates, or had secured visas to work abroad just prior to their accidents. Those who go abroad are said to respected by their local communities as they are able to send money back home to support their families, providing a level of income higher than what would be possible had they worked domestically in Nepal. Referring to her son who had died after not being able to afford a respirator:

> "*He was going to go abroad for work. We got a call while we were at [hospital] that his visa had arrived. He was going to work in Dubai, and then the accident happened.*"
> - Kumari

Due to ailments following their accidents, most men noted that it would not be possible to go abroad again, and would instead need to devise strategies to generate income from work activities in Nepal, but which would lead to a significant reduction in level of income.

Siblings of patients were also impacted by their family member's medical needs, forgoing opportunities to work abroad as an immediate need grew for them to support the household. Sarita's sister returned home from Dubai after her brother's accident, leading to loss of remittance-based income that supported the family in addition to her brother's income, which was also lost as he passed away:

> "*My younger sister was working in Dubai, which helped, but after she returned it got difficult for us.*"- Sarita

7. Concluding discussion

It's clear through review and analysis of patient accounts that the implications of experiencing catastrophic health expenditure are severe. The personal accounts of injury, experiences with the Nepali healthcare system, and resulting hardships presented are complex in nature, and have significant impact on the future prospects of patients and their families. They are also significant, as they signal factors related to healthcare that demand attention if Nepal is to successfully reach the stated goal of universal health coverage, as well as fulfil their duty to provide care to patients as part of basic human rights.

First, regarding patient-provider relationships and the pursuit for a proper diagnosis. It's clear through patient accounts that complying with medical provider guidance was enabled by trust, as doctors are seen as experts, and greatly influenced by the high-risk nature of patient needs. It would be difficult not to suspect that healthcare providers may be taking advantage of such trust and need states in some cases, as patients communicated being prescribed courses of treatment that were not beneficial, or in some cases even damaging to their already fragile state, yet demanding of great financial sacrifice. For others, lack of proper diagnosis compounded into more severe problems which could have likely been avoided had medical providers utilized proper services and technology to match the symptoms and need states of patients following injury.

A further dilemma is that of patients exhausting their finances throughout the pursuit of a proper diagnosis. When patients complied with medical provider direction, it often came at a high cost, both financially and on livelihoods, as families exhausted their financial savings, turned to loans, incurred high debt loads, and were left in difficult financial standing with money-lending family and community members. This was noted to have severe implications on patient family livelihoods, as non-male breadwinners who were forced to begin working in order to sustain household needs, and educations cut short in order to allocate tuition fees to the care of children's loved ones. For others, finances for high-cost scans, investigations, medicines and surgeries left them without financing for life-prolonging care such as being placed on a respirator, leading in one case to permanent brain damage that rendered a young man paralyzed, and leading to the death of another young man following a road-traffic accident and subsequent brain injury. Additionally, proper diagnosis may be established through utilization of standard processes and protocols, which would ultimately reduce risk of healthcare spending-related cycles of poverty and further health risk, as needs would be identified and treated much earlier than what most experienced.

Emphasis on rehabilitation following prescribe course of treatment was not emphasized by medical providers, despite patient accounts of its importance to their recovery. Three patients noted how rehabilitation offered through the NGO led to sensation returning to their extremities. It begs to question, after having gone through such a long journey to recovery, enduring high emotional, financial, and physical cost, why medical providers would not emphasize care that would assist in ensuring success of the treatments received.

Finally, land that was sold or offered as collateral in order to finance care created disruptions to modes of income-generation through agricultural and livestock activities, as the space used for such activities was no longer in the family's possession. Beyond disrupting prospects of income generation, and in some cases leading to family separation, this had an effect on the families perceived ability to be trusted by their community, as land could not be used as collateral to secure additional loans to finance further care as prescribed. This often pushed families back into a cycle of needing to finance care but without the means to do so. For one patient, this resulted in a cancer diagnosis, which was not provided until the fifth facility visited and over 680,000 NPR (6,100 USD) spent, leaving no further possibilities to finance chemotherapy needed to potentially save his life, and no clear path for how to potentially get there. Further, psychological toll experienced throughout the pursuit of care and strategies devised to finance it led in many cases to patients questioning the value of their life, as their struggles had contributed to the suffering of others. Few patients expressed how it would be better to die than to cause others to suffer.

Further research is therefore suggested to explore the following in greater detail: First, coordination mechanisms between healthcare facilities may work to ensure that patients receive the proper care needed when they are instructed to move to a new facility. Without such mechanisms, patients are simply passed around from facility to facility without a clear indication that they are on a path to improved health. With each new facility visited, patients must re-present their medical needs to providers, endure long wait times in order to be admitted, if at all, may not be admitted without utilizing personal connections, and they may not be prioritized due to lack of capacity and limited medical staff to assist them. Further, costs that are accumulated throughout the care cycle can exhaust any financing that could be put towards their future care, but instead are utilized to pay for earlier, less-than-beneficial care, in addition to transportation, housing, food, and medicines. Second, research on pricing for range of services could prove beneficial in working towards developing new pricing models and cost caps that match average income-levels of majority of population, as well as consistent pricing among public and private hospitals. Poverty cards are present in the country, which limit the amount that patients must pay depending on their noted economic status, but such a program was not often mentioned during patient accounts, suggesting that awareness and diffusion of the benefit is lacking. As majority of workers are involved in agricultural activities, often at subsistence levels to meet their family needs, the possibility to finance care through a for-profit system puts them at odds in receiving the care they need without needing to sacrifice their and their loved ones' livelihoods, while leading to grim outcomes where ability to repay loans are unlikely, creating tensions between family members, as well as between community members. Lastly, the prospects for provider accountability could be explored, in order to ensure that patients are not taken advantage of in their high need states or forcefully discharged after no improvements to their condition are seen. Many patients noted having undergone surgeries that did not address their greater need, yet mentioned no refund or credit for the costs already paid, but were instead left with outstanding need and large financial burden.

8. Appendix

8.1 List of interviews

Interview #	Date	Place	Type
1	05.02.2019	Kathmandu	Pilot/patient interview
2	08.02.2019	Mid-west Nepal	Patient interview
3	08.02.2019	Mid-west Nepal	Patient interview
4	09.02.2019	Mid-west Nepal	Patient interview
5	10.02.2019	Mid-west Nepal	Patient interview
6	11.02.2019	Kathmandu	Doctor interview
7	19.02.2019	Kathmandu	Patient interview
8	19.02.2019	Kathmandu	Patient interview
9	05.03.2019	Kathmandu	Patient interview
10	05.03.2019	Kathmandu	Patient interview
11	07.03.2019	Kathmandu	Doctor interview
12	21.03.2019	Kathmandu	Patient interview

Table 1: List of interviews by Matthew Moroni, 2019

8.2 Interview guide

Based on theoretical framework presented in section (4), interview guide was developed to structure interviews with patients, their caretakers, and healthcare providers. While utilized, interview guide was open-ended in order for patients to provide perspective and insight that interview themes might not have captured. The interview guide was developed in English alongside the translator, in order to ensure cultural and situational relevance, and was later translated by the translator into Nepali, which was then utilized during interviews. Interview guide in both English and Nepali are included below:

Interview guide – English: current or former patients of NHEDF
By: Matthew Moroni; Date: 2019.02.01

Priority themes to be discussed	
1. Injury/situation	1. Can you share about the incident? 2. After the incident, what events happened before coming to NHEDF? a. Ex: Visited local facility, stayed for a while until needing more care, maybe did not treat need right away due to inability to pay 3. Why did you choose to travel to KTM for care?

	a. Examples: Injury to serious for local heath post, services were too limited in village, medical need not properly taken care of. 4. How did you determine which healthcare facilities to visit for care? a. Wait times, location, recommendation of others, cost, quality of care
2. Financial situation: before, after	**Financial activities** 1. What kind of costs did you have to pay because of the injury? a. Stay and treatment at local health post, travel to KTM, admittance into hospital, investigations, treatments, medicines) 2. How did you pay for the costs? (Loans, sell land, forego child's education) 3. Did the costs make you unsure if you would choose to seek or continue the medical treatment? a. If so, how did you decide? (Age of person injured? Importance of family role? Gender? Daughter in law? 4. Did the costs for medical care have a big effect on your or your family's financial or living situation? a. Ex: Now in debt? Owe money to someone? Lost job? Relocate to new area to live? 5. Any other effects on your life because of your financial situation? a. Ex: Lost job 6. Will you/are you able to maintain your basic needs (pay your necessarily daily costs)? a. Ex: Food, housing, basic care
3. Life before and after injuries	**Daily life/activities** 1. What did you do on a normal day before the injury? a. Ex: Morning to evening. Worked, took care of family, school? 2. How did your family look before the injury? a. Ex: How many members, what kind of activities each person did. 3. Has your personal or family life changed since the injury? a. Ex: Hard to move around home and village, cannot do same activities as before without assistance b. Ex: Family is now split up, living in different locations? Move to new village for cheaper land? Family members now doing different activities with different responsibilities?

4. Social role/obligation	1. What kind of responsibilities did you/they have in your family and community? What kind of activities did you do? a. Ex: If father, were you working outside the home? Growing food for the family? Mother, taking care of children. b. Ex: Older man was in retirement age, but then adult son was injured, so the father had to start taking care of him. Role changed from being in older age towards retirement to now being very active and taking care of son full time. 2. Does your family/community put expectations on you to fulfill these normal responsibilities that you mentioned? a. Ex: To fulfill the demands connected to the role/responsibility 3. Are you able to fulfill your responsibilities/participate in your community in the same ways as before? a. Ex: Engage with local people, socialize as before 4. How does your family/community treat you? a. Do they treat you as always or has their attitude and behavior changed since your incident? i. Ex: Neglected, ignored because they are unable to fulfill their duties b. If changes, what has changed? What are the changes a result of? i. Ex: No longer together with family, father not able to work, mother must now take on more work/burden 5. Has/will your injury change how you interact with your family and/or community? a. Will you be seen in a different way? 6. Can you share if you have any thoughts or feelings about the change in your abilities/role, what kind of effects it has on you personally? a. Emotional burden, change in way they see themselves, impact their self-confidence and belief in their abilities
5. Outlook on future	1. What sort of future do you imagine for you/your family?

	a. Ex: How your daily activities have or will change because of injury? Where you will live if you must move? 2. Do you think your involvement in your family and community will be balanced and similar to before? Or will they change? a. Ex: Relocate to new village because land was sold, so no longer have local community, must meet new people, build new connections 3. If your/their situation has changed in significant ways, how will you/they cope? How will you manage? 4. Has your picture of yourself, or what the future might look like for you changed since receiving care at NHEDF? a. Ex: Self confidence, self image, view of self b. Ex: My future life now has more possibilities than I believed it would when I first had my injury
Tentative themes depending on time and flow of conversation	
6. Insurance/collective risk protection	1. Besides what has already been mentioned, did you have any financial assistance provided by the government or other program to help pay for medical care? 2. There are some services in Nepal where you can receive financial protection for you and your family up to a certain amount of money per year if you pay an annual fee. Have you heard about any such programs? a. Have you signed up for anything similar? 3. Do you know about the [Social Health Security Program (name in Nepali)] that can provide up to 50,000rs/family for annual fee of 2,500 rs? 4. If you're not signed up, would you sign up for such a program? a. If no, why not? Low income, negative perception of healthcare? Limited coverage? Unaware of what such programs provide?
7. Public hospitals vs. private hospitals	1. How did you choose what types of health facilities to visit? a. Ex: Location, quality of services, recommendation of other 2. Did you receive all previous care at public hospital or did you go to a private one? If private, why?

	3. Do you have opinions about the differences between public and private facilities? a. Ex: Quality, wait times, cost, effectiveness, treatment by staff 4. How did you feel about how staff talked to and treated to you at the facilities?

Interview guide – Nepali: current or former patients of NHEDF

By: Juliana Shrestha, in collaboration with Matthew Moroni; Date: 2019.02.01

अन्तर्वार्ता गाइड : हाल र पुर्व सेवाग्रही

१ चोट र स्थिति	१) तपाइको घटना बारे बताउनु हुन्छ? २) घटना पछि, NHEDF आउन अगाडी के भएको थियो? ३) तपाइले सेवा पाउन काठमाडौँ किन आउनु भयो? ४) स्वास्थ सेवा पाउन कता जाने भनेर कसरि छान्नु भयो?
२ आर्थिक स्थिति (पहिला र अहिले)	**आर्थिक क्रियाकलाप** १) तपाइलाई चोट लागेपछि के कस्तो खर्चहरु गर्नु पर्यो? २) तपाइले यी खर्चहरु कसरि तिर्नु भयो? ३) ती खर्चहरुले गर्दा खेरि तपाइलाई कहिले अब उपचार छोडौं जस्तो लागेको थियो? लागेको भए तपाइले कसरि निर्णय लिनु भयो? ४) के स्वास्थ सेवाका लागि गरेको खर्चले तपाइको परिवारको आर्थिक अवस्थामा केहि ठुलो असर परेको थियो? (ऋण, सापटी लिएको, काम छोड्न परेको, घर सरेको) ५) आर्थिक अवस्थाले गर्दा जीवनमा अरु केहि असर परेको छ? ६) के तपाइले आफनो आधारभूत दैनिक आवश्यकताहरु पुरा गर्न सक्नु हुन्छ ?
३ चोट लाग्न अगाडी र पछिको जीवन	**दैनिक क्रियाकलाप** १) तपाइलाई चोट लाग्न अगाडी तपाइको दैनिक जीवनमा बिहान देखि बेलुकी के के गर्नु हुन्थ्यो? २) घटना अगाडी तपाइको परिवार कस्तो थियो? ३) घटना पछि तपाइको परिवारमा केहि परिवर्तन आएको छ? (छुटेर बसेको, घर सरेको, परिवारका मानिसहरुको भूमिकामा परिवर्तन)
४ सामाजिक भूमिका र दायित्व	१) परिवारमा तपाइको / उहाको के जिम्मेवारी थियो ? कस्तो क्रियाकलापहरु गर्नु हुन्थ्यो?

	२) तपाइको परिवार / समुदायले तपाइलाई अझै पनि ति जिम्मेवारीहरु निर्वाह गर्ने आश गर्छ? ३) के तपाइले पहिला जसरि नै परिवाररसमुदाय प्रति आफनो जिम्मेवारीहरु पुरा गर्न सक्नु हुन्छ? ४) तपाइको परिवार / समुदायले तपाइलाई कस्तो व्यवहार गर्छ? क) पहिला जसरि नै व्यवहार गर्छ कि घटना पछि बदलेको छ? ख) बदलेको भए, कस्तो बदलाव आएको छ? किन बदलेको होला? ५) घटना पछि तपाइले आफनो परिवार र समुदाय संग अन्तरक्रिया गर्ने तरिकामा केहि परिवर्तन आएको छ? क) के तपाइलाई फरक नजरले हेरिन्छ होला? ६) तपाइलाई व्यक्तिगत रुपमा आफनो भूमिकामा आएको परिवर्तनले गर्दा कस्तो असर परेको छ? आफनो भावना र सोच बताईदिनु होस् ।
५ भविष्य	१) तपाइको विचारमा तपाइको र परिवारको भविष्य कस्तो होला जस्तो लाग्छ? (दैनिक क्रियाकलाप कसरि परिवर्तन हुन्छ? घर सर्न परेमा कहाँ बस्नु हुन्छ ? २) तपाइको परिवार र समुदायमा सहभागिता पहिले जस्तै हुन्छ जस्तो लाग्छ ? केहि परिवर्तन हुन्छ होला ? ३) तपाइको वा सेवाग्रहीको स्थितिमा ठुलो परिवर्तन आएको छ? परिवर्तन भएमा कसरी सामना गर्नु हुन्छ ? कसरी व्यवस्थापन गर्नु हुन्छ? ४) NHEDF मा सेवा पाए पछि के तपाइको आफुलाई हेर्ने दृष्टिकोण र आृनो भविष्यको लागि सोच बदलेको छ?

६ बीमा	१) छलफल भएका कुरा बाहेक, तपाइले अरु कुनै संस्था वा सरकारबाट स्वास्थ सेवाका लागि आर्थिक सहयोग पाउनु भएको छ? २) नेपालमा केहि सेवाहरु छन् जसमा तपाइले आर्थिक सुरक्षाका लागि हरेक वर्ष केहि पैसा तिरे बापत आर्थिक सुरक्षा पाउन सक्नु हुन्छ । के तपाइले यसको बारेमा सुन्नु भएको छ ? ३) के तपाइलाई सरकारको सामाजिक सुरक्षा योजनाको बारेमा थाहा छ? यस योजना बापत वर्षको २५०० तिरेर हरेक परिवारले ५०००० सम्मको आर्थिक सहयोग पाउन सक्छ । ४) यस्तो योजनामा के तपाइँ सहभागी हुन चाहनु हुन्छ? चाहनु हुँदैन भने किन?
७ सार्वजनिक र निजि अस्पतालको तुलना	१) तपाइले कुन स्वास्थ सुविधामा जाने भनेर कसरि छान्नु भयो? २) तपाइले पहिला स्वास्थ सेवा सरकारी अस्पतालमै पाउनु भएको हो कि निजिमा पनि जानु भयो ? ३) तपाइको सामाजिक र निजि सुविधाहरु बारेमा के विचार छ ? ४) त्यहाँका कर्मचारीले तपाईसंग कुरा गरेको र व्यवहार गरेको तरिका कस्तो लग्यो?

8.3 Consent form

A consent form was developed in order to inform patients of the nature of the study, notification of no benefits or incentives to be given, assurance of confidentiality, right to refuse to answer or to withdraw from interview at any point, how to obtain further information if desired. Further, consent forms were signed by both me as researcher and informant as interviewee, prior to audio-recording of interviews. The consent form was developed in English, translated by the translator to Nepali, printed, and physically signed by both parties. Copies of signed consent forms are available on request or as needed. The consent forms in English and Nepali are included below:

Consent form – English
By: Matthew Moroni; Date: 2019.02.01

INFORMED CONSENT FORM

In-depth interview with current or former patient of NHEDF or their family/caretaker

Date: ______________

Hello! My name is Matthew Moroni. I am a sociology student from Lund University in Sweden and a previous volunteer at NHEDF. I am here to conduct interviews with current or former patients of NHEDF to hear their stories and understand the impacts that paying for healthcare has had on their lives, their families and communities. Through hearing your story, I wish to bring awareness to the situations and challenges that individuals face when paying for medical care and hope to somehow make a positive change. I also aim to support NHEDF by bringing more attention to their efforts to help those in need.

Procedures

You have been selected for an interview because you are either a current patient, former patient, family member or caretaker of a patient who received care from NHEDF. I am asking for your participation in this interview in order to learn more about your/your family member's medical journey, challenges faced, and steps towards recovery that you or they have gone through. Information collected about you and/or your family during this study will be used to support my personal bachelor thesis research project and will not be shared with any other parties without your consent. With your permission, parts of your story may be used in NHEDF communications in order to support and bring more awareness to the organization.

I want to ensure that your privacy is maintained and ensure that the interview is convenient to you. I will request to audio record the interview to ensure that we capture all of the information shared in order to review at a later time. Audio recordings will be password-protected on a secure computer and will not be shared with others. The expected duration of the interview will be roughly one hour.

Benefits and incentives

There will be no direct benefit or payment given to you but the information you provide is likely to bring awareness to the challenges that patients and/or their loved ones experienced due to a significant medical need. I hope that the results of the study will help to improve medical services in Nepal and encourage more affordable possibilities to finance medical care without severely affecting the livelihoods of individuals and families.

Confidentiality

All the information you provide will be treated with strict confidence, used only for research purposes and to support NHEDF communications (if permission is given). In my final research paper, only first names will be used. I am greatly interested in and value hearing your story, views and perspectives and encourage you to be very open and honest. You are not expected or pressured to respond a certain way, but are free to share and say what you wish.

Right to refuse or withdraw

You may refuse to answer any question or choose to stop the interview at any time. However, I hope that you will answer the questions and participate in a conversation with me/the translator as you feel comfortable to do so.

Who has reviewed this project?

This project has been reviewed and approved by my education supervisor, Mr. Axel Fredholm at Lund University and Mr. Samrat Basnet of NHEDF.

Who to contact

If you have a question or concern about any aspect of this study, you may ask or tell Matthew before or during the interview or contact Samrat Basnet.

Do you have any questions about what I have just told you?

[ ] YES: ____

[ ] NO: ____

Do you agree to take part in the study?

[ ] YES:

____

[ ] NO: ____

Do you agree to have your/your family's story shared through NHEDF communications?

[ ] YES: ____

[ ] NO: ____

Comments:

____

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Declaration of the participant

I have understood the purpose of the research study. I have read or been read the above information. I have had the opportunity to ask questions and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate in this study and understand that I have the right to withdraw from the study at any time.

<u>If agreed:</u>

Name and signature of participant	Date
Name and signature of person obtaining consent	Date

Consent form – Nepali
By: Juliana Shrestha, in collaboration with Matthew Moroni; Date: 2019.02.01

सूचित सहमति फारम

NHEDF का सेवाग्रहि (हाल वा पुर्व) वा सेवाग्रहिको परिवारसंग in-depth अन्तर्वार्ता

मिति :

नमस्कार! मेरो नाम म्याथिउ मोरोनि हो। म स्वीडेनको लुन्द विश्वविद्यालयमा समाजशास्त्रको विद्यार्थी हुं, र मैले पहिला NHEDF मा स्वयमसेवकको रुपमा काम गरेको छु। अहिले म यहाँ NHEDF का हाल र पुर्व सेवाग्रहिहरु संग अन्तर्वार्ता गरेर, उहाँहरुको कथाहरु सुनेर, स्वास्थ सेवाको लागि गरेको खर्चले गर्दा आफनो, आफनो परिवार तथा समुदायमा भएका असरहरु बुझ्न आएको छु। तपाइको कथा सुनेर, यसरि स्वास्थ सेवालाई खर्च गर्दा भोग्नु पर्ने स्थिति र चुनौतीका बारेमा बोध गरेर, केहि गरि एउटा राम्रो परिवर्तन ल्याउने यो मेरो प्रयास हो । मेरो उदेश्य NHEDF को कामलाई ध्यानमा ल्याई यस्तै अरुलाई मद्दत पुर्याउने हो ।

कार्यविधि

तपाई NHEDF को हाल वा पुर्व सेवाग्राही वा सेवाग्राहीको परिवार हुनु भएको कारणले तपाइलाई अन्तर्वार्ताको लागि छानिएको हो । मैले तपाइको र तपाइको परिवारको मेडिकल यात्रा, त्यसमा भोग्नु भएका चुनौती तथा स्वास्थलाभका लागि लिनु भएका कदमहरु बारे बुझ्न अन्तर्वार्ता गर्न खोजेको हुँ ।

यस अध्ययनमा तपाई र/वा तपाइको परिवारका बारेमा जम्मा गरिएका जानकारीहरु मेरो आफनो स्नातक थेसिस अनुसन्धानमा प्रयोग हुन्छन् र तपाइको सहमति बिना अरु पक्षलाई दिईदैन । तपाइको अनुमतिमा तपाइको कथाका केहि भागहरु NHEDF ले संस्थालाई टेवा दिन प्रयोग गर्न सक्छ ।

म यस अन्तर्वार्तामा तपाइको गोपनियता र सहजता निश्चित गर्न चाहन्छु । म यस अन्तर्वार्तामा भएका सबै जानकारी संकलन गर्न आवाज रेकड गरि पाउन अनुरोध गर्छु । यसो गर्दा मैले पछि गएर अन्तर्वार्ताको समिक्षा गर्न पाउने छु । आवाजको रेकड एउटा कम्प्युटरमा पास्वोर्ड सहित सुरक्षित राखिने छ र अरुलाई दिइने छैन । यो अन्तर्वार्ता लगभग एक घण्टाको हुने छ ।

फाईदाहरु
तपाईलाई कुनै प्रकारको प्रत्यक्ष फाइदा वा भुक्तानी हुने छैन । तपाइले दिनु भएको जानकारी बापत महत्वपुर्ण मेडिकल सेवा प्राप्त गर्नमा सेवाग्राही तथा उनको परिवारले भोग्ने चुनौतीहरु बारे बोध गराउन मद्दत गर्छ । मलाई आशा छ कि यस अध्ययनका नातिजाहरुले नेपालका स्वास्थ सेवाहरु सुधार्न र व्यक्ति तथा उसको परिवारको जीवनमा गम्भीर असर नपर्ने गरि स्वास्थ सेवामा लगानी गर्न सक्ने विकल्पहरु सिर्जना गर्न प्रोत्साहन हुन्छ ।

गोपनियता
तपाईले प्रदान गर्नु हुने सबै जानकारी गोप्य रहने छन् र अनुसन्धानका लागि तथा NHEDF को संचारमा (अनुमति पाए बापत) मात्र प्रयोग हुने छन् । मेरो अन्तिम अनुसन्धान रिपोर्टमा तपाइको पहिलो नाम मात्र प्रयोग हुने छ । म तपाइको कथा सुन्न, भाव तथा दृष्टिकोणहरु जान्न धेरै इच्छुक छु र तपाइले खुलेर अनि इमान्दार भएर बोल्नु हुन प्रोत्साहन गर्छु । तपाइले कुनै एक ढंगमा प्रतिक्रिया दिनु पर्छ भन्ने छैन, तर तपाईलाई मनमा लागेको कुरा बताईदिनुहोला ।

अस्विकार गर्ने हक
तपाइलाई कुनै प्रश्नको उत्तर नदिने र अन्तर्वार्ता कुनै पनि बेला रोक्ने हक छ । तथापि मलाई आशा छ कि तपाइले प्रश्नहरुको उत्तर दिनु हुन्छ र छलफलमा म र मेरो अनुवादकसंग सहज रुपमा सहभागी हुनु हुन्छ ।

यो प्रोजेक्ट कसले समिक्षा गरेको छ?
यस प्रोजेक्टले मेरो शिक्षक लुन्द विश्वविद्यालयका अक्सेल फ्रेडहोम तथा NHEDF का सम्राट बस्नेत बाट समिक्षा र अनुमोदन पाएको छ ।

कसलाई सम्पर्क गर्ने ?
यदि तपाइलाई यस अनुसन्धानको बारेमा केहि प्रश्न भएमा म्याथिउलाई अन्तर्वार्ता अगाडी वा हुदै खेरि सोध्न सक्नु हुन्छ, वा सम्राट बस्नेतलाई सम्पर्क गर्न सक्नु हुन्छ ।

यस बारेमा तपाइको केहि प्रश्न छ?
छ [ ] ____
छैन [ ] ____

के तपाई यस अध्ययनमा सहभागी हुन सहमति जनाउनु हुन्छ ?
हुन्छ [ ] ____

हुँदैन [ ] ____

NHEDF को संचारमा तपाइको र तपाइको परिवारको कथा राख्न सहमति जनाउनु हुन्छ ?

हुन्छ [ ] ____

हुँदैन [ ] ____

टिप्पणी

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सहभागीको घोषणा

मैले अनुसन्धानको उद्देश्य बुझेको छु । मैले माथिको जानकारी पढेको छु वा मलाई पढेर सुनाइएको छ । मलाई प्रश्न सोध्ने मौका दिइएको छ र मैले सोधेका प्रश्नहरुको उत्तर पनि सन्तुष्ट रुपमा पाएको छु । मैले यस अध्ययनमा स्वयम् सहभागी हुन सहमति जनाउँछु र मैले कुनै पनि समयमा यो अध्ययन छोड्न सक्ने हक रहेको कुरा बुझेको छु ।

समहती भएमा

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सहभागीको नाम र दस्तखत

मिति ______________________

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सहमति लिने व्यक्तिको नाम र दस्तखत

मिति ______________________

References

Books/Articles

Askvik, S., Jamil, I. and Dhakal, T. (2010). Citizens' trust in public and political institutions in Nepal. *International Political Science Review*, 32(4), pp.417-437.

Coveney, J., Meyer, S., Rogers, W., & Ward, P. (2008). Trust in the health system: an analysis and extension of the theories of Giddens and Lehmann. *Health Sociology Review*, Vol 17, pp 177-186).

Edwards, B., Foley, M. W. (1997). Social Capital and The Political Economy of our Discontent. *American Behavioral Scientist* 40(5): 668-677.

Fukuyama, F. (1995). *Trust: the social virtues and the creation of prosperity*. New York: Free Press 1995. Retrieved from http://ludwig.lub.lu.se/login?url=http://search.ebscohost.com.ludwig.lub.lu.se/login.aspx?direct=true&db=cat01310a&AN=lovisa.001481289&site=eds-live&scope=site

Gerhard, U., Knijn, T., and Lewis, J. (2002) 'Contractualization' in *Contested Concepts in Gender and Social Politics*. Cheltenham: Elgar, pp.105-135.

Ghimire, M., Ayer, R., & Kondo, M. (2018). Cumulative incidence, distribution, and determinants of catastrophic health expenditure in Nepal: results from the living standards survey. *International Journal for Equity in Health*, 17, 1–12. https://doi-org.ludwig.lub.lu.se/10.1186/s12939-018-0736-x

Giddens, A. (1991). *Modernity and Self-Identity: Self and Society in the Late Modern Age*. Stanford: Stanford University Press.

Hänninen, M. (2018). *Recycling on the local level in Thailand: influence of trust, norms and social networks*. Undergraduate. Lund University.

Meyer, S., Ward, P., Coveney, J. and Rogers, W. (2008). Trust in the health system: An analysis and extension of the social theories of Giddens and Luhmann. *Health Sociology Review*, 17(2), pp.177-186.

Mishra, S. R., Khanal, P., Karki, D. K., Kallestrup, P., & Enemark, U. (2015). National health insurance policy in Nepal: challenges for implementation. *Global Health Action*, Vol 8, Iss 0, Pp 1-3 (2015), (0), 1. https://doi-org.ludwig.lub.lu.se/10.3402/gha.v8.28763

Mohanty, S. K., Agrawal, N. K., Mahapatra, B., Choudhury, D., Tuladhar, S., & Holmgren, E. V. (2017). Multidimensional poverty and catastrophic health spending in the mountainous regions of Myanmar, Nepal and India. *International Journal for Equity in Health*, 16, 1–13. https://doi-org.ludwig.lub.lu.se/10.1186/s12939-016-0514-6

Moroni, M. (2019). *Patient care cycle,* Lund, created 12 May 2019.

Moroni, M. (2019). *List of interviews,* Lund, created 12 May 2019.

Möllering, G. (2001). The Nature of trust: from Georg Simmel to a theory of expectation, interpretation and suspension. *Sociology*, 35, 2: 403-420.

Okamura, M., Bhandary, N., Mori, S., Marasini, N. and Hazarika, H. (2015). Report on a reconnaissance survey of damage in Kathmandu caused by the 2015 Gorkha Nepal earthquake. *Soils and Foundations*, 55(5), pp.1015-1029.

Parnwell, M. G. (2007). Neolocalism and renascent social capital in northeast Thailand, *Environment & Planning D: Society & Space*, 25, 6, pp. 990-1014, Urban Studies Abstracts.

Pokharel, B. (1970). Gender roles and activities among the rural poor households: Case studies from hill villages. *Occasional Papers in Sociology and Anthropology*, [online] 7, pp.65-82.

Punch, K. F. (2005). Introduction to Social Research - Quantitative and Qualitative Approaches. 2nd ed. London: SAGE Publications Ltd, pp.193-231.

Putnam, R. D. (1993). *Making Democracy Work: Civic Traditions in Modern Italy*. Princeton University Press 1993

Rantalaiho, L. (1998) 'Verniwung van het Sociaal Contract' (Renewing the Social Contract) in [Verslag Symposium, *Vrouwenarbeid 100 jaar later*, Den Haag: Ministerie van Sociale Zaken en Werkgelegenheid.] *Contested concepts in gender and social politics*. Cheltenham: Elgar, pp.105-135.

Saito, E., Gilmour, S., Rahman, M. M., Gautam, G. S., Shrestha, P. K., & Shibuya, K. (2014). Catastrophic household expenditure on health in Nepal: A cross-sectional survey. *Bulletin of the World Health Organization, 92*(10), 760-767. doi:10.2471/blt.13.126615

Shakti, S. (1995) in *Occasional Papers in Sociology and Anthropology*, [online] 7, pp.65-82. Available at: https://www.nepjol.info/index.php/OPSA/article/view/1111/1589 [Accessed 19 May 2019].

Webpages

Data.worldbank.org. (2019). *Rural population*. [online] Available at: https://data.worldbank.org/indicator/SP.RUR.TOTL.ZS?locations=NP [Accessed 21 May 2019]. (Data.worldbank.org, 2019)

Government of Nepal, (2011). Nepal Living Standard Survey. (pdf) Government of Nepal, Central Bureau of Statistics. Available at http://cbs.gov.np/sectoral_statistics/poverty/nlssurvey2010_11. Accessed 2018.10.01.

Government of Nepal, (2016). Nepal Health Sector Strategy. (pdf) Government of Nepal, Ministry of Health and Population. Available at http://nhsp.org.np/nepal-health-sector-strategy-2015-2020/. Accessed 2018.10.03.

Government of Nepal, (2017). Social Health Security Program. (pdf) Government of Nepal, Social Health Security Development Committee. Available at http://dohs.gov.np/wp-content/uploads/2017/09/Health-Insurance.pdf. Accessed 2019.04.02.

Kullabs.com. (2019). *Health Services Available in Nepal*. [online] Available at: https://www.kullabs.com/classes/subjects/units/lessons/notes/note-detail/1004 [Accessed 23 May 2019].

Nepal Labour Market Update. (2017). *International Labour Organization*. [online] Available at: https://www.ilo.org/kathmandu/whatwedo/publications/WCMS_543497/lang--en/index.htm . Accessed 2019.05.21.

NHEDF. (n.d.). Nepal Healthcare Equipment Development Foundation. Available at https://www.nhedf.org.np/. Accessed 2018.10.01.

United Nations, (n.d.). UN Web Services Section, Department of Public Information. Available at http://www.un.org/sustainabledevelopment/health/. Accessed 2018.09.25.

World health Organization, (2010). Health systems financing: the path to universal coverage. (pdf) Available at http:// www.who.int/whr/2010/en/. Accessed 2018.09.30.