CASE REPORT

A 15-year-old Nepali boy with metastasised colorectal cancer

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SUMMARY

Nepal suffers from vast inequalities in modern healthcare. The low-income country wrestles with far-reaching insufficiencies in minimal preventative medicine, health awareness, limited infrastructure and difficult topography—all of which contribute to poor access and poor care-seeking behaviour. Our patient came from rural Nepal, where primary healthcare outposts are frequently understaffed and underequipped. He received supportive treatment in his village from the time symptoms presented until he was diagnosed 2 years later, at a tertiary medical centre, with colorectal cancer. An examination of the relevant literature indicates that younger patients often present in later stages of the disease due to initial misdiagnosis or overlooking colorectal cancer as a possibility. Beyond the rarity of the patient's condition, the logistical and financial obstacles he faced in Nepal, particularly outside of the capital of Kathmandu, deterred his access to a higher level of care and delayed his correct diagnosis and treatment.

CASE PRESENTATION

A 15-year-old Nepali male presented to the surgical outpatient department with a 2-week history of rectal bleeding, generalised abdominal pain and a 10 kg weight loss in the past 6 months. On physical examination, a large tender mass was found in the lower left quadrant of his abdomen, as well as swollen external haemorrhoids. The patient noticed the abdominal mass 2 years earlier, but was now most concerned about his rectal bleeding. He stated that the mass has grown in size since he initially noticed it.

The patient had previously visited a rural health post, close to his home, for abdominal pain management. No referral to a hospital was made at the time. The patient assumed that his symptomatic presentation was not serious enough to warrant the referral; however, physicians at Kathmandu Model Hospital cited the insufficient training of health post workers as the likely reason for not having referred this patient to a tertiary healthcare facility. The lack of access to a medical doctor also makes it unlikely for health post workers to know when to refer a patient to a higher level of care.

During his time at home, his mother used local healing methods hoping that these would make the pain subside and resolve the abdominal mass.

There was no family history of colorectal cancer or rectal bleeding; a grandfather suffered from lung cancer.

On admission his haemoglobin level was 6.7 g/dL, platelet count of $496 \times 10^9/L$ and carcinoembryonic antigen (CEA) of 36.76. Urine samples were unremarkable, and stool samples were positive for occult blood. Adenocarcinoma of the colon was suspected.

On the second day of admission, the patient underwent a colonoscopy, but physicians were only able to reach the sigmoid colon where a single polyp was observed. On his fourth day, an explorative laparotomy was conducted where carcinoma of the sigmoid colon as well as extensive metastasis to the peritoneal cavity, liver surface, diaphragm, omentum and small bowel was seen. Anastomoses between the descending colon and the distal sigmoid colon was performed, as well as a resection of the omentum. A ureteric double "J" stent was placed in the right ureter; however, it was impossible to place a stent on the left side. The stent placement was limited by the obstruction of the ureters that developed during the patient's stay in hospital.

Finally, the pathology report confirmed a mucinous adenocarcinoma of the sigmoid colon, which was poorly differentiated showing invasion through the serosa (T3). Presence of omental deposits and several signet-ring cells were also seen. The tumour metastasised by direct invasion to adjacent organs. No haematological or lymphatic spread was noted. Staging of this patient has been defined as IVB (4b) with spread to more than one distant organ.

This is a rare presentation whereby the age of the patient, the presence of poorly differentiated cells, signet-ring cells, staging and the extensive metastasis denote a poor prognosis.^{1–4} The patient was discharged and referred to an oncological centre to start chemotherapy treatment in the following 3 weeks.

GLOBAL HEALTH PROBLEM LIST

- ▶ Health education
- ▶ Primary care in rural areas and a formal referral system
- ▶ Retention of healthcare workers in rural areas
- ▶ Recognition of non-communicable disease symptomatology by primary healthcare workers
- ▶ Access to tertiary care facility
- ▶ Funds and transport to a tertiary care facility

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GLOBAL HEALTH PROBLEM ANALYSIS

Nepal is a developing country, which has tried to establish a preventative and affordable healthcare system since 1978, especially for those of low socioeconomic status and in rural areas.⁵ Currently, only 17% of the population of Nepal live in urban areas⁶; 86% of these urban-dwellers have access to a hospital or primary healthcare centre (PHCC) within 30 min walking distance in contrast to 59% of rural households, which are, on average, 135 min away from such facilities.⁷ The organisation and distribution of healthcare facilities found in Nepal is as follows. From bottom up, we find health posts, PHCC, district hospitals, zonal hospitals, regional hospitals and then central hospitals. On the municipal level, health posts (which merged with subhealth posts) provide basic care as health assistants who are usually paramedics manage them. Each electoral constituency that is a political unit within a district should have a PHCC; therefore, a district may have more than one PHCC. PHCCs are required to have a licensed doctor present for diagnosis, treatment and/or referral of patients, providing a higher level of skill than that found in health posts. District hospitals fall under the District Health Office and can provide larger facilities with more advanced and specialised care.⁸ Zonal, regional and central hospitals provide progressively more specialised level of care. The distribution of facilities and manpower varies across geographic areas, providing certain areas with more adequate care than others.

Since the Nepalese declared 'Basic Health as a Human Right' in the Interim Constitution of Nepal in 2007, a Free Healthcare Policy (FHCP) has been progressively introduced across healthcare facility echelons throughout the country. These free essential services focus on maternal health, outpatient, as well as emergency care and cover a set number of medications.⁹ The provision of free healthcare to the Nepalese population is a move designed to bridge the gap in access to healthcare throughout the socioeconomic ladder. In recent years, certain shortcomings in the implementation of this plan have been underlined. These include logistical issues such as manning health posts and PHCCs, shortages of medicines for long periods of time and delayed reimbursements.¹⁰

Nepal struggles with the limited number of trained personnel in health posts and PHCCs in rural areas. It was assessed that approximately 25%–40% of health posts are unmanned, most of them present in rural areas; and between 10% and 40% of health workers assigned to a post were absent from the facility during the conduction of the survey.¹¹ Poor implementation of monitoring and supervision of the health facilities, healthcare workers and the qualifications of the latter have contributed to the inconsistencies in quality of care, especially in rural areas. The level of training of healthcare workers in health posts has been reported to be insufficient to diagnose illnesses that warrant referral to a higher level of care.¹⁰ The issue of poor referral has been noted across the healthcare strata. A cash incentive has been developed to encourage referral of underprivileged populations, pregnant women and patients with TB, HIV/AIDS or mental illnesses from district health centres to higher levels of care. Other free healthcare programs have been designed as a means to increase access to care of at risk populations, but the fragmented healthcare system, inconsistency in availability of services and lack of public awareness of the programs leave them underused.¹² Furthermore, limited communication between health posts and higher level health centres was determined to be a logistical problem that has prevented the referral of patients to more appropriate healthcare facilities.

The Human Resources for Health Strategic Plan 2011–2015 aims to improve the referral system from rural health posts to appropriate health institutions with adequately equipped and trained personnel.¹³ Alongside the existing plan to improve access to care, we recommend the creation of supervisory boards to regularly assess infrastructure, medication availability, training and distribution of healthcare workers across healthcare facilities, emphasising the hard-to-reach areas of Nepal.

Internal migration, from rural areas to urban areas, retaining of the healthcare work force in urban centres, as well as migration from Nepal to high-income countries, offer insight into the reasons for the dearth of medical manpower in rural areas.¹⁴ This trend has been observed in other low-income countries where the majority of healthcare personnel is staffed in central and developed locations, leaving the majority of the population living in rural areas medically underserved.¹⁵

It has been suggested that factors that discourage healthcare personnel from choosing to work in rural outposts include: low government wages, poor infrastructure with lack of medical equipment and medication, lack of coworkers, being overworked, safety, community support and meagre educational and job opportunities for family members.¹⁶

The paucity of medical doctors in rural areas has also been linked to the high tuition fees of medical education in private universities that cannot be reimbursed with low public wages. It was reported that 89.9% of healthcare resource training in Nepal is provided by private institutions. This has been attributed to the lack of budget or organisation on the part of the public sector. These private institutions are often poorly monitored and do not encourage their trainees to enter the public sector health force.¹⁷

An encouraging step towards the decentralisation of healthcare practitioners has come from The Patan Academy of Health Sciences (PAHS). Established in 2008, this institution has dedicated itself to selecting, training and dispatching medical students during their MBBS to rural areas around Nepal. PAHS preferentially enrolls students who show an interest in working in remote areas after graduation. Over the years, this institution has developed a rapport with district governments, local non-profit organisations where they have training sites in order to further lasting relationships between the local community and the incoming trainees. The school incorporates classes on understanding specific health needs of communities, regional language and cultural practices. This model of education emphasises taking individual accountability while working towards the greater good of the entire Nepali population.^{18 19}

The Government of Nepal has also addressed the issue of recruiting and retaining healthcare workers in rural areas. Since the establishment of the Health Service Act in 1997, incentives have been implemented in order to encourage health workers to practice in rural areas. One such incentive requires a 2-year minimum work experience in a rural area before a government health worker may be considered for a promotion. Health workers who have practised in a variety of geographical areas are prioritised for scholarships and training opportunities.²⁰ Recently the Nepalese government put into effect a 2-year mandatory rural service requirement for medical students receiving scholarships in the hopes of bridging the gap and preventing the loss of medical students to developed countries. Furthermore, the government is covering partial or full tuition fees of medical students who will commit to working in rural areas.²¹ These steps are encouraging as they acknowledge the population's need and present solutions. Yet recent graduates still face the challenges of poor infrastructure in these rural healthcare facilities, including lack of laboratory facilities and

medical equipment, limited access to colleagues, supervisors and communication via telephone or internet.²² It is important to address these limitations to ensure a sustainable and desirable environment for healthcare workers.

The diversity of castes, dialects and culture within the Nepali society varies across geographical areas. Graduates from the Kathmandu Valley institutions might not be versed in these nuances, which only adds to the difficulties of working in these areas. Ninety-six per cent of academic institutions are located in urban areas, which creates a bidirectional barrier: people from rural areas are less likely to gain access to education and, on the other hand, concentrating healthcare workers in these areas is problematic.¹⁷ The high costs, distance and poor communication makes it difficult for people from rural areas to attend centrally located institutions for training. PAHS prioritises the acceptance of these populations into their training programme. This is a means of providing these particular communities with trained professionals who are fluent in their dialect and cultural practices. Those graduates are then three to four times more likely to return to their communities after medical training.¹⁹ Furthermore, this institution is committed to assisting its alumni who choose to practice in rural areas by providing support via telemedicine and the creation of lasting relationships between the medical professionals, the local community leaders and the government.²³

Attraction and retention of medical personnel in rural areas has become increasingly problematic in middle- and low-income countries, in general. Improving living conditions, working environment, competitive wages, career development and collaborations opportunities, education and healthcare access for the family of personnel are crucial points, which should be addressed by the government.²⁴ In light of these factors, it should be suggested to the Nepalese government that further investment in economic incentives, the local environment, housing, as well as the work environment in the rural areas could entice the workforce to stay in rural locations and decentralise medical staff. Although the government has publicised its intention to decentralise medical care, budget allocation and spending still heavily favour the centre as compared with the rural periphery.²⁵ Tertiary care services are provided by a limited number of public hospitals, mostly located in Kathmandu. They are manned with health-workers, nurses and physicians of various specialties.²⁶ The majority of the medical manpower and facilities are found in Kathmandu Valley, leaving the rural areas with minimal manpower, few diagnostic tools or medication at their disposal.²⁷

In Nepal, non-communicable diseases (NCD) account for 80% of the outpatient population and 42% of all deaths (35% of these are caused by cardiovascular disease, cancer, respiratory diseases and diabetes).^{28–30} A 2013 STEPwise approach to surveillance (STEPS) survey in Nepal assessed NCD risk factors in order to establish a continuous monitoring system, as no national NCD registry system currently exists.^{31 32} In developing countries, the consequences of NCDs on a household can drain financial resources, lead to the loss of the primary breadwinner, and the decision to forego treatment in order to provide for the rest of the family. The principal means of financing healthcare expenses, especially for chronic diseases, in Nepal is through out-of-pocket expenditure, as only certain medications and interventions are covered by the FHCP.⁹ Due to the high cost of NCD treatment, the Nepal Health Sector Programme-1 (NHSP-1) did not include them in its essential healthcare service package. As the burden of such diseases is on the rise, the NHSP-2 included an expansion of health promotion activities to prevent certain NCDs by encouraging lifestyle changes.³³

Colorectal cancer (CRC) is the third most common cancer in both sexes, and the second leading cause of cancer-related deaths in the USA.³⁴ The recorded incidence of CRC in South-east Asia is currently on the rise though still lower than that of developed regions of the world, but presents with poorer survival rates.^{35 36} Generally associated with an older population, incidence of CRC in young Nepalese adults was reported to account for 28% of all CRC cases, which presents an unusual trend. Similarly to our case, colorectal cancer in young patients tends to manifest itself initially with abdominal pain and rectal bleeding.³⁷

The current American Cancer Society screening guidelines for CRC recommend a flexible sigmoidoscopy every 5 years and a colonoscopy every 10 years for a population between the ages of 50 and 75.³⁸ Screening is one of the best ways to reduce the incidence and mortality of cancers, such as colorectal and cervical, yet no population-based screening programs have been put into place in the majority of the low-income Asian countries. In recent years, screening programs for CRC have been set up in Japan, China, South Korea, Hong Kong and Taiwan, targeting the population aged 50–70 years. The primary screening method used in these countries is faecal occult blood test (FOBT) or immunochemical FOBT (iFOBT) with the poorly implemented follow-up, for patients who test positive, with colonoscopy. These programs have proven to be effective in lowering the mortality of CRC as it is detected in the early stages and can be treated appropriately.³⁹

In a country like Nepal, where access to basic medical care can be challenging, we have found no evidence of a nationwide screening programme for colorectal cancer. Additionally, low cancer awareness, poor access to healthcare services, a general lack of presence and affordability of treatment all contribute to delayed care seeking behaviour and presenting in late stages of disease.⁴⁰ Access to a specialist, endoscopy, surgery, chemotherapy and radiotherapy for timely diagnosis and treatment are expensive and sparse. In resource poor settings, infrastructure, training of healthcare professionals and public awareness campaigns for prevention and treatment of cancer must be part of a nationwide intervention if a truly meaningful reduction in disease burden is to be realised.

In the past years, the highest prevalence of CRC in young patients has been in Asia.⁴¹ Retrospective studies have found that CRC in the young localises predominantly in the left colon and rectum, as was observed in our patient.^{42 43} In young patients, CRC is more likely to be found in those with a heritable syndrome as compared with sporadic cases of disease.⁴⁴ As previously mentioned, the delay in diagnosis of young patients, who have sought care, has been linked to the lack of suspicion of this disease and mistaking the symptomatology for haemorrhoidal or other benign diseases. Furthermore, patients from developing countries often seek symptomatic relief in traditional medicine, again delaying the presentation to healthcare institutions. Though we do not suggest the implementation of a large-scale screening intervention for CRC in young patients with no family history of the disease, we do encourage educating healthcare professionals and the population at large on its symptomatic presentation, especially in regions of the world where CRC is on the rise in the younger population. Consistent with our patient's presentation, the three main reported symptoms in young patients with CRC are rectal bleeding, abdominal pain and changes in bowel habits.⁴⁵ Physical examination, flexible sigmoidoscopy, digital rectal exam and further work-up should be made available to symptomatic patients with or without family history of colorectal cancer.

Since 2010, the national guideline for cervical cancer screening in Nepal has emphasised the need to prioritise the incorporation of screening programmes in the national health policy and reproductive health schemes. The age standardised rate of cervical cancer in Nepal is 19 per 100 000, which is one of the highest in South Asia.⁴⁶ The Papanicolaou smear screening test is the standard in developed countries to detect cervical dysplasia and cervical intraepithelial neoplasia, though the 2010 Nepali government protocol emphasises using visual inspection with acetic acid.⁴⁷ Both methods have been difficult to implement across the board. The current policy targets PHCCs as a starting point for screening while emphasising the importance of a referral system for women needing specialised care. The restricted infrastructure, limit in trained manpower and budget allocation hinder accessibility to screening women.⁴⁸ The barriers to health seeking behaviour, with regards to cervical cancer screening, have been: limited education, poor familial support, social stigma, indifference during the asymptomatic phase and poverty. Women, particularly from poor households, are not sufficiently screened for cervical cancer because of limited access to healthcare facilities, lack of education and relying on traditional remedies.⁴⁹

Public education initiatives, like other government efforts that have been mentioned in this text, represent a move in the right direction for the Nepali people; yet significant problems in implementation and supervision of projects are still a major viability limitation. Furthermore, emphasis should be placed on decreasing costs and increasing the presence of screening programmes in poor and rural areas. By looking at the initiation of a large-scale screening and treatment programme of an NCD in Nepal, we can better appreciate the logistical issues and barriers to be overcome to better such a programme and further develop interventions targeting other NCDs.

The issue of NCD management is not a high priority one, with only 0.7% of Nepal's total budget in 2011 allocated towards it.⁵⁰ Currently PHCCs offer limited preventative or management services for NCDs, due to the absence of training of healthcare workers, lack of diagnostic tools, and available medications mostly geared towards acute conditions.⁵¹ Of the 70 medications available in the primary healthcare package, only three are related to NCDs.⁵⁰ In tertiary level hospitals and specialised

facilities, two hospital beds per 10 000 people are dedicated to curative health services.⁵¹

In Nepal, cancer patients have access to medical treatment within seven hospitals, five of which offer radiotherapy services. The limited locations for screening and intervention lead patients to present to medical facilities in later stages of disease.^{52 53} The centralization of specialist care delays diagnosis and treatment of patients with cancer, as in the case of the patient we have presented. Though colon cancer screening for such a young patient is not done routinely in any part of the world, access to a versed healthcare worker in NCDs, specifically cancer, might have shortened the delay in presentation and referral to a higher level of care. Currently, there is no population-based cancer registry system in Nepal; therefore, determining the exact prevalence of disease cannot be established. However, based on data from major hospitals, the annual incidence of cancer is between 8000 and 10 000.⁵⁴

The Government of Nepal and NGOs have conducted public health awareness campaigns, which are broadcast via television, radio, printed materials and lectures to inform the population of health risks, encourage cancer prevention, detection and treatment.⁵⁴ The Nepal Cancer Relief Society (NCRS) works on both cancer awareness education as well as a mobile screening programme that it conducts annually, predominantly in rural areas. Regarding treatment, the NCRS subsidises partial or full treatment costs and travel costs for patients in financial need.⁵⁵ These are encouraging steps towards bringing care to an underserved population; yet a more consistent countrywide programme with government funding is necessary.

A high-impact, countrywide NCD prevention and intervention programme could be established in primary healthcare settings to promote health education, early detection and treatment thereby reducing the need for more extensive and expensive interventions.⁵⁶ In order for such a programme to be established, a restructuring of PHCCs would be necessary to insure a more consistent standard of care. Furthermore access to medical equipment, broadening of NCD specific medication and free healthcare coverage should be present throughout all geographic areas in Nepal. These variables all contribute to poor preventative care and lack of healthcare seeking behaviour (figure 1). Both the National Health Policies and the National Health

Figure 1 Social determinants of health in Nepal.

Sector acknowledged the need for increased health promotion concerning NCDs but problems persist in the implementation of their projects. The Package of Essential NCDs intends to increase the list of essential drugs available, improve the competency of primary healthcare workers in managing NCDs and develop a three-tier referral system for NCD management.⁵⁷ A referral system is present in most primary healthcare facilities, although patient compliance after referral is low and inversely correlated with the distance from the tertiary healthcare facility.⁵⁸

In addition to the heterogeneous distribution of medical facilities and staff in Nepal, the hilly and mountainous landscape as well as the lack of infrastructure makes transportation across the country very arduous. During monsoon season, the difficulty is exponentially greater, with landslides and heavy rains blocking all transport along muddy roads. Additionally, only an unreliable public transport network is available in rural areas. Cities are served relatively better. Rail and air transport are unaffordable to the rural population.⁵⁹ The lack of access to hospitals in the larger cities may mean missing days of work in order to be seen.

With 29% of the rural population falling under the poverty line as compared with 8% of the urban population and a GDP per capita of \$1500 (2013),⁶⁰ financial means for transportation, room and board to seek medical care in the capital put a huge burden on the rural population. Though some financial help for the very poor is available in certain tertiary facilities, most of the financing for healthcare services is paid for out-of-pocket.^{61 62} This means that medical procedures are conducted according to the financial abilities of the patients. The price of transportation and the loss of income during time spent in hospital can be enough to deter a person from seeking a higher level of care.⁶³

Our patient came from a rural area where he visited a health post. His lower quadrant mass was not palpated by the health worker, thus the tumour was missed, and the patient was not referred to an appropriate healthcare centre. The patient was given over-the-counter pain medication and natural remedies made by his mother to manage his abdominal pain. According to the patient and the patient's mother, the cost of transportation, the duration of the 12 hours bus ride, the loss of income, leaving the household for an undetermined amount of time, the lack of cancer awareness and the hope that the abdominal mass would dissipate delayed their trip to Kathmandu Valley to access proper medical care. Although his family has been able to finance his stay in hospital as well as surgeries and medication, future patient compliance with chemotherapy will likewise depend on the family's finances. The required regimen of chemotherapy is not fully subsidised by the government.

Another issue is the patient himself, who was not made aware of his health status. In Nepali culture, health status is disclosed to the family of the patient, who then choose how much information to divulge to the patient. This patient was told he was healed following the explorative laparotomy and was discharged in supposed good health.

The physical, financial and logistical obstacles that people in Nepal face to access care is often a heavier burden than the suffering from the disease itself. The impetus for this patient's arrival in hospital was the initiation of rectal bleeding, after which the incidental finding of his metastasised colorectal cancer was found.

Currently, there are some changes being made in an attempt to overcome the lack of medical *savoir-faire* on the part of rural healthcare workers. Kathmandu Model Hospital, along with other city hospitals, set up teleconferences with remote clinics in order to bring the expertise of medical doctors in the hands of the health workers or general practitioners in these areas.

Teleconferences have been used to instruct rural staff members to properly stabilise patients as they await transfer to city hospitals. Remotely, rural doctors can be guided through medical and surgical procedures with which they are unfamiliar, as well as receive feedback from the larger medical community. Furthermore, regular teleconferences are held between Kathmandu Model Hospital and hospitals across Asia to develop better e-Health and Telemedicine system, specifically designed to reach the rural areas with scant access to health facilities. The changes being made in Nepal are encouraging yet a more consistent application of solutions reaching the rural population need to be systematically put in place and monitored.

Learning points

- ▶ Advanced disease presentation due to limited access to proper care in rural areas.
- ▶ Centre for higher level of care are concentrated in the city of Kathmandu.
- ▶ The financial burden of healthcare can limit the degree of patient compliance.
- ▶ Using technology in order to bring medical knowledge to isolated areas.

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