



TRAGEDIES AVERTED

Mariam Mehdi

A *Heartfile* Publication

French speaking, Mariam Mehdi, hails from Mauritius. She has, however, adapted to life in Pakistan since many years. Her work in the field of development, health care and social work reflect her empathy with the disadvantaged in Pakistan.

Her association with Heartfile and her concern for victims is reflected in the narratives that link the patients described in her book. Her aim is to advocate for the right to health care for vulnerable groups.

Mariam Mehdi has delved deep into the lives and problems of poor, hospitalised patients. She has worked with intense compassion and with reflection and examination of the health care system in which these patients are often victims. Mariam has written about patients who have been plagued with physical and psychological problems and connected with them to observe their noble resilience in the face of adversity. As a result, she has been filled with hope and confidence in the civilizing spirit of humanity.

Mariam Mehdi pays homage to the individuals depicted in her collection of stories and to those doctors, care-givers and well-wishers who reach out to them. She looks forward to an awareness of the suffering and pain of the poor on the part of all of society so that society itself may become a powerful instrument of change in the Pakistani health care system and in the alleviation of the country's poverty.



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The Author

Mariam Mehdi has wide experience in the field of development, especially of women and their issues. Her work spans more than three decades. She has also headed a refugee program in Pakistan, a program which was the largest hub of refugee resettlement in the world. It successfully saw several Afghan, Iraqi, Iranian and Somali refugees seeking asylum, to other countries. In this book, she has used the lens of violence against women, refugee and IDP tribulations, discrimination against minorities and bonded labour, to look at what is silent, what is hidden and what no one talks about. This is based on her empirical experience.

She is a committed humanist. She joined Heartfile, an NGO offering financial help to patients in distress, on a voluntary basis, which led to her current assignment. When she took on the onus of recording and documenting the stories of patients who were medically affected and who were provided support from Heartfile, she did not know the heartaches and misery she would encounter while recording the stories. Her firm resolve to complete the task is a quality few people can boast.

When Mariam joined Heartfile as a volunteer she was not aware of the tremendous emotional effort that would be required to engage in conversations to learn of some of the heart-rending stories of patients, both men and women, who were unable to find medical help. This medical help from Heartfile became available to them after she had assessed their situation and ascertained their need with the help of doctors.

This book is a compilation of accounts of such individuals, across the provinces of Pakistan, who were suffering with little or no hope of survival without medical help. It was Mariam Mehdi's relentless efforts that connected Heartfile and the victims.

About Heartfile

Heartfile is a non-profit Non-Government Organization (NGO) which was established by Dr. Sania Nishtar (<http://www.sanianishtar.info/>), Founder and President, in 1998. It is a think tank with a focus on analytical work and innovative solutions for improving health systems in order to achieve universal health coverage in Pakistan and other developing countries.

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Dedication

This book is dedicated to the many patients who shared intimate and painful information with me...

and to

Dr. Sania Nishtar, who is a founder of causes and a fighter for change; a woman with ideas and ideals, courage and creativity, whose pursuits are marked by the intensity of her commitment.

Mariam Mehdi

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Preamble

This book is the result of a collective vision. A vision that Dr. Sania Nishtar dreamt of fifteen years ago. A voice that broke the silence when she decided to change the course of her career and chart her own path. She had the courage to stand up for her own beliefs, to engage in and contribute to the cause of those deprived of the right to health care. This realization enabled her to take action and ultimately assume a leadership role, nationally and globally, to fight for the rights of poor patients. Her passion and laser-sharp focus has driven her to great achievements and inspired others to envision a better, more just health care system that does not yet exist in Pakistan, but hopefully will do so one day.

Voices from within her led her to set up Heartfile Health Financing (HHF), an organization which is woven with her strength and hope, in order to make a difference in the lives of those who are deprived and suffering. This book is a testimony to all associated with Heartfile who have silently observed the birth of the organization, its infancy and adulthood. It is through these lens that we see Heartfile's journey.

Heartfile's journey of fifteen years seems like an entire lifetime. This organization is under the leadership of a committed individual and has the support of several others. Heartfile Health Financing (www.heartfilefinancing.org) is one of the many initiatives of Heartfile. Heartfile Health Financing is a health financing program. It provides financial support to those who are either unable to pay for, are likely to spend catastrophically, or who become mired in ruinous debt while seeking health care, or those that risk foregoing treatment altogether, if not supported.

Heartfile Health Financing's process, which is driven by mobile phones, provides assistance with dignity for patients, speed for health providers and unprecedented transparency for all its partners, including donors. Heartfile Health Financing is currently operational in selected hospital wards in Pakistan and is undergoing evaluations for expanding further.

Heartfile Health Financing has made a difference to the lives of many women, children and men. HHF has not aimed at playing the omnipotent benefactor, neither is its aim to set up institutions and infrastructure. This must be the responsibility of the state. Instead, Heartfile has attempted to make contributions in ways which could set an alternative for the poorest of the poor.

I must first thank all the patients who allowed me to feel the pulse of their pain and suffering and who so generously shared the most intimate parts of their lives. I thank Dr. Sania Nishtar, who has always been so encouraging and without whose unrelenting enthusiasm this book would not have been possible. I also thank our generous donors for their support and for their belief in our efforts to make a difference in a cause they care so deeply about. This book shows how our work has changed the lives of patients. I am grateful to the team of professionals of HHF for their hard work and dedication.

I also thank (late) Rati Cooper and her sister, Perin Boga, for their proof-reading of the manuscript. I am grateful to Anushka Rustomji and Amna Pataudi for volunteering to do the illustrations.

Mariam Mehdi

Islamabad

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Introduction to Testimonies

This book is a collection of stories of some of the cases supported by Heartfile Health Financing (HHF) during the early days of the program's operations in 2011-2012, when I joined the organization as a volunteer. I had the privilege of meeting these patients, to assess their eligibility to get support from HHF.

The book chronicles individual cases of poor patients' sufferings. It is part of the HHF initiative to identify, assist and address the problems of very poor patients who urgently need financial support for immediate medical care, using a rights-based approach.

This book is for everyone. For all of us who walk past the government hospitals of Peshawar, Rawalpindi, Islamabad, Lahore and Karachi. For those who have suffered intensely due to accidents and diseases which have maimed them for life and for those who ignore the right of the poor to health care and do not want the topic mentioned. This book is for every man or woman who lives a life of privilege – the privilege of not living with the constant anxiety of pain and suffering, the privilege of not facing the pangs of hunger and deprivation, the privilege of having all economic opportunities reserved as their natural domain.

Heartfile Health Financing is devoted to assisting troubled people with sincerity. This book is an eye-opener for all of us who are inactive, who just stand by, silently watching. However, there are others who dive into action. They are the ones who make a difference and add a rich meaning to their own lives and the lives of others.

The book touches on these issues through simple language; it captures the ordeals, the plight, tribulations, pain, struggle and sufferings of poor patients whose right to health care is denied. It aims to transport the reader to the bedsides of poor patients. These patients are at various hospitals from the most troubled areas of Pakistan and Afghanistan but are on common ground in their plight and share the problems of poverty, lack of health care and deprivation.

This book is for all who wish to intervene and fight for the right to health care. Patients have a right to have access to health care which is a human right. We must help them heal. The experiences of patients reflect the cycle of poverty and deprivation which is degrading in itself. The hardest thing about poverty is that it makes people the target of ridicule. It is time to shrug off the smug, complacent mask and face reality. Finally, this book is an ode, an ode to Heartfile and to all those who daily make its existence possible.

I was drawn into the lives of numerous patients through the assessments that measure their poverty level. My volunteer 'job' – the privilege and pain of it – is to capture instants, moments of pain, mental and physical suffering, on the page with words. A page is such a meagre space to record the intensity of the pain, poverty and deprivation each patient endures.

Heartfile Health Financing steps in to make a difference in the life of a poor patient when his/her helplessness is conveyed to us. Gradually a bond develops between the patient and the volunteer. Patients open up and confide, often breaking down as they narrate an incident about their plight and their lack of finances for health care.

These stories, these personal testimonies, reflect how patients have been marked, how their families have been impacted, by ill-health. Their confidences reveal the feelings, attitudes, resilience and dignity of poor patients and their families, regarding the reality which surrounds them. More specifically, the stories address issues of poverty and all its attendant needs, survival, pain and suffering.

Social exclusion and marginalization are prevalent in every case. These stories provide a holistic view of the patients being deprived of access to health care. The process of developing the stories required a face to face involvement with the patients and their attendants, while recording aspects of the patients' lives, both past and present. The central themes from the information analysis are related to poverty, deprivation and health impoverishment; to the social construction of patients' lives, their relationships, their loss, and their concept of themselves as they undergo their suffering.

These narratives are threads that weave the lives of patients. The creation of this book is an important component in understanding our patient and is a means towards the promotion and maintenance of a better and just system. It is hoped that this culture of listening and sharing will promote a positive effect on patients who, through disease and accidents, have often broken from their previous lives, resulting in feelings of pain, isolation, anonymity, loss of identity and loneliness.

These patients had a desire to tell their stories and actively constructed their own narratives. Reflecting on our notes of these assessments meant reading real life experiences of pain. Their sharing was painful. Each patient had his/her own language and own manner of narration. We could feel the pain unfolding. We could sense the sudden pangs of suffering. Each patient spoke despite the pain and hurt but the written page of their narrative takes on a life of its own, beyond the moment of their telling.

The need has been to record the stories, each one a different version of the will to survive and to have a normal life. We appreciated the openness, especially of the women who bared hearts and souls. Looking at these patients' feelings, suffering is not hard to find. It is visible in the eyes of the father whose 12-year-old urgently needs a bone marrow transplant, leaving him to plead to others to help his son; It is woven into the helplessness of Aisha who is mentally challenged, a 40-year-old destitute woman who is forced to beg on the streets for survival; It appears with sadness across the profile of a patient of each minority group.

Gratitude was not hard to find in their words, nor in their eyes. It seemed to be a natural response to our compassion. A truly beautiful discovery for us was to find so much love in anger. Anger caused by the violation of a basic right, the right to health care. It was a two-pronged, death-defying love that challenged the unfair conditions of life and focused on the injustice that divides the nation into two sides: the wealthy and the vulnerable. To re-create these lives as clearly as possible on a page and reflect on their suffering and deprivation, was a challenge. These patients were not case files but breathing souls, flesh and blood.

Heartfile started operations in 2010 as part of an initiative to identify and address the problem of health impoverishment. The financial assistance of Heartfile is intended to contribute to the process of healing, hope and support. This initiative has a commitment

to walk a long road in serving a cause and making a difference in the lives of poor patients in distress. This commitment to a noble cause has been a rewarding experience and has contributed to the spiritual growth of all who have taken part in it. It has been a means of finding one's own voice when one has witnessed injustice, cruelty, poverty, suffering and deprivation. While at the level of simple discourse all agree on the need for a policy and implementation of a just and sound system, there is little understanding of the actual problems of health impoverishment. Programs address manifestations of the problem rather than the problem itself. It is here that Heartfile's role becomes extremely significant.

Marginalized Patients



In this book, I have divided patients' stories into five categories. The first category outlines accounts of Marginalized Patients. These patients are socially excluded, are victims of a cycle of disadvantages interwoven with poverty, gender and ethnicity-related issues. They are deprived of their most fundamental and basic right to health care. Many of the patients are part of migrant, homeless, slum communities living in urban poverty and persistent neglect. Discrimination, stigma and abuse against marginalized groups impact their ability to access a quality lifestyle. They are deprived of opportunities and can hardly advance socially. Inequality circumscribes every aspect of their existence. The stories depict the various contours of inequality; recourse to justice is a distant possibility; they are vulnerable to neglect and are voiceless.

ANWAR BIBI – OSTEOPOROTIC FROM A MINORITY COMMUNITY



Anwar Bibi, the sole earning member of a family of eight, slipped at work and sustained a hip-bone fracture. Hip fracture is more common among women as they are prone to osteoporosis (loss of bone tissue), a disease that weakens the bones. Women experience about 80% of all hip fractures.

Anwar Bibi was completely immobile, unable to get up or even move around in bed. Despite this, she was not given medical care immediately and was only taken to the hospital four days after the accident, when she could not bear the pain anymore. X-rays showed a fracture of the hip: she needed surgery. A partial hip replacement was avoided in her case as Anwar

Bibi was in her late forties and had an active life; a hip replacement would have worn out in such an active person. The treating surgeon opted for a hip pinning, which is a procedure that involves placing several screws across the fractured bone. The procedure required an incision on the outside of the thigh. Using the X-ray to guide the surgeon, several screws were passed across the fracture in order to stabilize the broken bones. Rehabilitation was initiated immediately and walking was advised so she could return to her normal life at the earliest.

Anwar Bibi belonged to a minority group which was the poorest and most marginalized and she lived in a slum area in despicable conditions. She was already marginalized for being a woman and further discriminated against for being a Christian.

There are and have been a number of very distinguished Pakistani Christians but by and large they are poor and restricted to sanitation work and other menial jobs. Many Christians originally came from the lowest ranks of the old caste system. These social divisions persisted post-Partition. Discrimination and harsh treatment made them receptive to the preaching of missionaries. Technically, it is not a religious problem; it is a caste problem. They are often subject to systematic discrimination at the hands of society.

Anwar Bibi was further burdened by a sick spouse and a disabled son who suffered an electric shock while at work. Although she was the employee of a semi-autonomous corporation, she did not avail of any sick leave or medical assistance. Her salary was deducted for the days she did not work. Being from a minority Christian community in Pakistan, she was not entitled to seek the social protection assistance of the Zakat Fund or Bait-ul-Mal. Heartfile Health Financing's policy is to help anyone, regardless of religion, caste, nationality or gender and therefore there was no difficulty for Anwar Bibi's family to seek help from Heartfile.

During Heartfile's assessment, Anwar Bibi's nineteen-year old daughter said that she was willing to work to contribute to the family income but was not allowed to do so by her disabled brother. This showed that, in spite of the family's dire straits, an adult woman had no decision-making power, but rather was controlled by a male member of the family – who himself was contributing nothing. Clearly, there is a need to change the mindset because

here is a woman – a mother and a wife – who, although the only wage-earning member and in principle the female head of a household, had actually no control over her income and life. She was provided with health care. She was the poorest of the poor, economically near the bottom of the 70% of the population which does not have coverage for health care expenses in Pakistan.

In this story the issues – of exclusion of minority groups, of poverty, of the unjustified power of males and the power they have over women and of exploitation at work and the insensitivity of employers – make the case more complex. The extent of deprivation and the nature of social exclusion had a major impact on the health care of Anwar Bibi. She was part of the worst-off group in socio-economic terms and seems to have experienced the worst health outcomes. The irony is that Pakistan does have equality laws for people of varying faiths but there are serious issues in the implementation of these laws.

This case highlights the issue of the minorities and the desperate situation they are in. They are often considered second-class citizens and are discriminated against. Furthermore, health impoverishment adds to and exacerbates already existing social disadvantages among minorities.

CHAN SHAH - HIT BY A MOTORCYCLIST

Chan Shah, a frail 76-year old man, was motionless and distraught on a bed in the common ward at the Benazir Bhutto Hospital's (BBH) Orthopaedic ward in Rawalpindi. He had sunken, hazy eyes and a wrinkled face. He had met with a traffic accident and sustained a hip fracture. Hip fracture is one of the most common osteoporotic fractures: bone density is lost with advancing age in both men and women, leading to an increasing risk of fractures.

Chan Shah had been hit by a motorcyclist who drove on without stopping, in Attock. Chan Shah had been travelling from his village to beg. Beggary is a prevalent social problem in South Asia and begging has been accepted as a way of life. Begging was not his family tradition but he had no option when he could no longer earn a living any other way. He had his own location for begging, which he called 'his territory', in front of the main mosque of the city and he said that he had to guard and defend it. With the accident, he was fearful that he might not be able to go back to begging and would lose his source of income.

Over the years, he had mastered the art of begging and being a city-beggar, he was able to earn enough to complement the offerings of the village community. Chan Shah was an 'independent beggar'; he did not belong to a 'gang' or live in a 'beggars' colony'. He would commute to the city as the money there was better than begging in the village. He would return home at the end of the day, though he would not beg every day of the week, not having the strength to do so. Fridays were important earning days: the income was higher as many would attend Friday prayers and were more inclined to give alms on that day. He was decent in his attire — in spite of the fact that his clothes were rags — and appropriate in his behaviour. He begged in the name of religion; he had grown a beard and was always in front of the mosque at a strategic location and thus seen by most worshippers. He begged to feed himself and his wife and was able to survive through the kindness and generosity of strangers.

He said life in old age had been very painful. In his younger days he had a better life as a fishmonger, but now old age and poverty had added to his miseries. He had a look of resignation and helplessness. Memories brought tears to his eyes and his voice quivered as he shared his anxieties. After the accident he had been left lying by the roadside until he was picked up by a passer-by and taken to the local hospital. He was later referred to the BBH for further treatment of a hip fracture. His skinny limbs and emaciated physique were a reminder of hardships endured and his ragged clothes spoke volumes for his poverty. Unattended and distressed, he pleaded to be helped as he was very poor and in pain. He was so helpless that he called on the sympathy of other patients' attendants in the ward. His income from begging was so small that neighbours in the village occasionally offered Chan Shah and his wife food. His wife, a diabetic patient, had become blind in one eye due to lack of medical treatment and so was not much of a support. Chan Shah said that he was well-respected in the village and often provided spiritual guidance to the villagers.

Chan Shah was a destitute old man with no regular source of income, someone who lived at the mercy of his community's generosity. In the village, as his total resources were depleted by poverty, the social network, backed by the generosity of individuals, intervened and a call was made to Heartfile to assist in paying the cost of his hip surgery. He had been filled with worry as to how he would pay for the treatment and medicines and also as to how to manage recovery so he could avoid becoming more dependent on outside resources.

The traffic accident had changed the life of this patient, leading to his total loss of independence, income and confidence. It had long-term and given his age, perhaps final disruptive effects, on his former economic and social activities. He continued more than ever to live on the margins of society. In his old age, poverty with its deleterious effects on his health, had become the centre of Chan Shah's life. Heartfile was able to play a small part in alleviating some of his suffering by paying his medical bills.

EJAZ - HOMELESS

Although men are more likely to become homeless than women, homelessness is a lot more gender equal than most people believe. The primary causes of homelessness – poverty, lack of affordable housing, unemployment – affect all, regardless of gender. Ejaz had been constrained by several barriers, including lack of information, poor access to social networks, inadequate health services and inability to pay. He was stigmatized more severely again for being homeless and poor. Thus, the two issues combined, had contributed to a negative perception and a social rejection that seriously impacted Ejaz.

Ejaz was the victim of a hit-and-run accident which occurred in Kharian. He sustained a left leg fracture and was left lying on the road until the highway police picked him up and took him to the Edhi Centre. There he remained, unattended, as the small staff at the already overcrowded centre was overworked. During the next three weeks he was given little medical care in spite of his excruciating pain. He was finally admitted to another hospital after the intervention of the chairman of the Zakat Committee during his visit to the centre. He arranged for Ejaz to be admitted to the Pakistan Institute of Medical Sciences (PIMS) in Islamabad. Prior to this hospitalization, Ejaz had been provided with below-standard treatment and only self-medication, which worsened his health, thus creating a vicious cycle.

In the accident both his tibia (the stout, triangular shaped bone that does the load-carrying work of the leg) as well as the fibula (the long thin bone which attaches the knee and ankle to the outside of the tibia) had broken. The injury resulted in a prolonged hospitalization and infection developed in the tibia from the open wounds over the fracture. Pins were placed into the bones to put them in the correct position and stabilize them for healing. Ejaz was condemned to a lengthy bed confinement at the hospital and to protracted immobility. However, he was lucky to have received prompt orthopaedic and other medical treatment at PIMS, thus preventing the very real risk of future disability.

Ejaz suffered loss of wages due to the accident as he was a daily wage earner. He was already destitute and lived in a tent by the roadside. He had no family. After the accident, he went into further debt and was dragged into ever-deepening poverty. The incident was catastrophic in terms of both his health and his finances. Ejaz helped us to discover the truth about human connection, the reality of what was happening to him as he was deprived of all means of help. Both in the hospital and on the roadside, he called 'home', his fellow men's lack of connection with him was at once symbolic and actual. This isolation was palpable.

This case portrays the reality of the homeless around us; a man without a permanent place to call home or a stable source of subsistence. He said that he was not born into homelessness but fell into it at a young age after he lost both parents. He could not even sustain the most basic needs: this was a crushing blow to his dignity and this physical injury added to and complicated his inner turmoil. The driver who inflicted the injury, who left Ejaz for dead, was the first human interaction he had had for some time. He had had a life of continual uncertainty, not knowing whether he would have enough to eat each day or whether he would be evicted from his temporary shack. This is the ultimate form of insecurity.

Poverty had led him to abandon all pursuits in life. He said he knew that he was caught in a cycle of hopelessness. His plight would certainly not end with Heartfile's assistance, but this would at least show him that someone had reached out to him and given him hope. He was so deeply grateful. Society and the State must play a role in helping the homeless like Ejaz to get back on their feet – they should not be abandoned to exist in a permanent cycle of poverty. Ejaz, like many others, is trapped by progressing deficiencies and escape becomes heartbreakingly difficult, if not impossible.

SHAH JEHAN - FEAR OF THE UNKNOWN

There was fear of the unknown – of the disease and of the public outside her door. Shy, Shah Jehan tried to conceal herself behind her chaddar, which is a traditional garment of Muslim women, consisting of a long cloth that envelops the body from head to foot and covers all or part of the face.

She felt as if she had been thrown out into the world, all alone and unprotected while suffering great pain. At the same time, she was determined to fight and survive all the odds laid down against her by the disease and her fate. She had been unwell for the past six months with pain in the chest, swelling and shortness of breath. She was weak, had lost weight and had no energy.

She was from a very remote village of the Bajaur Agency which is currently aflame with Taliban insurgents and their supporters. She could not access any health care facility, as such was almost non-existent. She had to be relocated to Peshawar for specialized care.

Her X-ray and CT scan revealed a mediastinal mass, a growth within the chest cavity. Due to the location of the mass in the mediastinum, the growth, if left untreated, could cause complications, including invading the heart. In general, such tumours are rare. Mediastinal tumours are usually diagnosed in patients between 30-50 years, but they can develop at any age and form from any tissue that exists in or passes through the chest cavity. In adults, most mediastinal tumours occur in the anterior (front) mediastinum and are generally malignant (cancerous) lymphomas or thymomas. Thus, the case of Shah Jehan could be of serious concern.

A mediastinal mass excision to further investigate the nature of the tumour was urgently requested from Heartfile and granted. The procedure, which is a mediastinoscopy with biopsy (performed under general anaesthesia) is the examination of the chest cavity through a lighted tube inserted through a small incision under the chest bone; a sample of tissue is taken to determine if cancer is present.

This twenty-five-year-old mother with three children and a migrant worker spouse, was homeless. She was hospitalized only when she became increasingly ill. She had lived a desperately hard life without shelter.

She said that she and her children were bearing the brunt of problems of living in poverty, being homeless and sick. She was additionally burdened with caring for her elderly and sick in-laws, as well as her children. She was left with little time to care for herself.

The hazardous living conditions had certainly contributed to her ill-health. Migration in search of better wages was the main driving force for her husband to relocate to Karachi. He was a manual labourer working on a meagre salary of Rs.5000 per month, away from home and so he was not able to be at her bedside to attend to her or their young children or his aged and infirm parents. It would be difficult if not impossible for her to move out of poverty without a secure and permanent home and a reliable income.

She shared the following: “My children are being denied the chance of going to school. They may never go to school. I had to turn to loan sharks who charge high interest rates, and this has further impoverished me. Being a woman from a very, very conservative region, I am socially excluded. I often cry silently. I am very worried about my children. If something happens to me, who will take care of them? It depresses me.”

Shah Jehan had the multiple roles of wife, mother and daughter-in-law. Her chronic ill-health had tampered with her self-image, her self-respect and self-worth; all eroded now she could no longer provide care to her family. The narrative of her experiences reflected how her health status had impacted the once normal, although poverty-stricken, life she had led.

The sickness and hospitalization without any support from her spouse, made her go through a very turbulent period. Her entire life thus far had been consumed with caring for others. She had experienced extended periods of very low income, great depths of poverty and of ill-health. She had been confined within the four walls of the house in which she lived after her marriage, amidst cultural and religious barriers that kept her secluded and

then she was suddenly exposed to the alien environment of a hospital bed, confronted by strangers, medical practitioners as well as other patients.

An uncle who temporarily gave her the refuge of one room without kitchen or toilet, out of sympathy, had escorted her to Peshawar and left her in the hospital unattended. Her youngest child of three was with her in the hospital while the other two were with the grandparents.

A sick woman such as Shah Jehan is devalued in society. She is heavily burdened with responsibilities and has to tolerate so much misery in life. She suffers silently as she is expected to serve others without caring for her own health. She had been the caregiver, the care-provider until she fell sick. She ignored her ailment and hid it till it became intolerable. Her strenuous work was the reason her illness took a serious turn. She mentioned that she had to please everyone and still be at their mercy.

There was great turbulence in her life and she was unable to reconcile the discrepancy between her ideals and her actual life; between her dreams and reality. She was fighting against her destiny. Poor health was a cost she had to pay and she silently suffered both physical and emotional agony.

Poverty is a primary cause of homelessness. The links between homelessness, poverty and the lack of access to proper health care contributed to and exacerbated Shah Jehan's ill-health.

BAI KHATOON – THE FACE OF URBAN POVERTY

Homelessness is the worst form of urban poverty and social vulnerability. No one chooses it. Women experience homelessness worse than men. While the phenomenon of homelessness violates the most basic of human rights for anyone, women without a home and living on the streets suffer the most severe kinds of abuse and violence. The majority of homeless women are left to fend for themselves and they form one of society's most marginalized constituencies. The government should take urgent action to protect their human rights and prevent their further abuse and marginalization.

Bai Khatoon lived in a village near Talagang not far from Rawalpindi. As was the custom, she was married off at the age of fourteen. She bore the stigma of being mentally challenged and was soon abandoned by her spouse. She must have been strong, however, to have exercised her decision-making power to move to the city, where she would have to fend for herself. She sought employment but her disability was a disadvantage in finding a job as a domestic worker in people's homes. Her only recourse to support herself was to beg on the streets of the city.

She was homeless without even the basic shelter of an unfinished shanty house. She was able to join the homeless community of an area outside the city, built by slumlords who have made vast profits from building shacks on contested land, using the notoriously corrupt police to protect their investments and exploit the poor dwellers. She had been living there for the past six years. She lived in a shack that could barely keep the sun and rain away but was in close proximity to the city where the opportunities were. She ended up drifting in urban slums and became part of a floating population.

She was comfortable begging. She stated she begged for three days and went back when her earnings were spent. Her needs were basic. She said that her existence was on a day-to-day basis. By living on her own she seemed to have developed her own defence mechanisms. She lived amidst the homeless community by choice. Being part of the community, she felt

it appropriate to intervene in a fight that broke out one day between two men, in order to pacify them. Little did she realize that she would come out a victim. Her right wrist was fractured by a blow from a stick.

She was dropped at the hospital and lay unattended in the ward for over two weeks without any financial or moral support. Heartfile intervened when her case was referred by the treating doctor. Within hours she was assessed and her case was swiftly approved. As she said, “If I am not helped, I will have to go back to my shelter, maimed with another disability and perhaps this time not even be able to continue begging for a livelihood.”

What was most clear about this lone woman was her resilience, her determination to struggle and help herself in spite of the social ostracism attached to begging and homelessness. She had demonstrated courage and confidence; she seemed uninhibited by her disability and the social stigma.

On a follow-up visit the next day, we found that she had been operated. Heartfile’s financial investment in her treatment had gone a long way — its impact on her was great, both emotionally and physically. It is again a situation where the rapid, small-scale intervention of Heartfile prevented a minor crisis from becoming a catastrophe.

Lack of adequate housing had made Bai Khatoon more vulnerable to violence. She had initially suffered from forced eviction and become homeless. She complained of persistent poverty and abandonment by her husband, resulting in her being thrown out of a home and onto the streets. A woman without family in Pakistan is among the most vulnerable and a woman without a family or a home is ten times more vulnerable than a man.

SIDRA - A SLUM DWELLER

Tears welled up in the eyes of the father as he related the illness of his ten-year-old daughter and his inability to meet the cost of her treatment. Lean, pale and restless, Sidra tossed on a hospital bed in pain. The paper-thin girl, extremely undernourished, seemed to be deprived of all the amenities of life. She had inherited the poverty, disease and despair of her parents. Her father and a distant relative seemed almost equally sick and malnourished.

She looked lost in another world, sad like her parents. Her world was comprised of the impoverished slums where she and her family of nine lived the nightmares that the father described. Slums were the reality for them, their only home, where they would spend all their lives. For them, the father added, life was worse than death. Thus, they barely survived, totally deprived of a dignified life. Even water had to be fetched from a distant well. They were the most disadvantaged, living in a deprived area without any support or infrastructure, without water or sanitation.

Sidra had pneumonia which developed into a painful complication called an empyema – an infection of the lungs. She was suddenly seized with severe pain in the left side, seemed very ill and got rapidly thinner. Emaciation is often rapid and extreme in empyema in children, especially the poor and malnourished. The parents could not afford private treatment and she was brought to Lady Reading Hospital and admitted immediately, after several tests and X-rays. Financial assistance, which was immediately approved, was requested from Heartfile for decortication. With the family's small income, it would have been impossible for them to pay even part of the cost of the treatment.

Sidra came from a very humble, illiterate family who were living in basic rented accommodation in a slum area on the outskirts of Peshawar. Her father was a manual labourer on daily wages; A young brother of seven had also been sent out to work in the urban outskirts as a scavenger, in order to complement the household income. No money was coming in except this child's daily income of Rs. 80, as the father was attending to his daughter, Sidra. The scavenging brother was himself most certainly exposed to

contaminated objects, as well as long hours of work, respiratory and skin diseases and human abuse.

Child labour is a major socio-economic problem in Pakistan: this was a small child roaming in garbage and climbing into waste-bins, being exploited and paid a pittance. His was a childhood ruined by the desperate family necessity to earn money. Pakistan is signatory to the ILO Convention on the Worst Forms of Child Labour (No.182) and ratified this in 1990. However, not much is done towards implementation.

The family suffered the trials and tribulations of life - a sick child and the necessity of sending another to forage for scraps. They were bowed down with the burden of misfortune. Sidra's father stated that for him hope was a rare commodity and the sudden illness of his child had been a frightening experience for the family. The economic and social impact of poverty and illness is far-reaching. Ending child labour demands courage and societal will.

WAJIHA - A COLLAPSED WALL

A fatal accident occurred during heavy monsoon rains when the wall of a veranda collapsed, and the roof caved in on Wajiha. Neglect, the age of the structure, poor drainage and the flooding of the roof by heavy rains caused the wall and roof to collapse. The roof was already in bad shape as the house was old and dilapidated with numerous cracks in the walls. Wajiha was in the veranda when it collapsed and she had to be pulled from under the rubble.

She sustained a penetrating injury in the thorax. She was rushed to the emergency department of Lady Reading Hospital. A test tube placement for drainage was the first step in the management of the injury. It was thought that simple drainage was all that was required. She was incubated but had to return a month later as the injury led to a hazy haemothorax on the right side of the chest. She developed dyspnea and fever and clotted haemothorax (blood in the chest cavity) through the thickening of the chest.

The failure of the initial procedure to adequately drain the blood resulted in residual, clotted haemothorax that would not drain via a test tube. If left untreated these retained hemothoraces could become infected and would likely lead to an empyema formation.

Wajiha's attendant kin said that the pain associated with the injury had made breathing difficult. Wajiha was a beautiful fourteen-year-old girl. She always looked happy. She was a bright and confident girl with her whole life ahead of her. She was kind, sensitive, thoughtful and wise beyond her years. She was adored by all. After the mishap she looked pale and distressed. In addition, she was malnourished.

This was caused by the absolute poverty of her circumstances; she lived in rented accommodation, without the basic facilities of kitchen, water or toilet, in a slum area on the outskirts of Peshawar. Her father was a vegetable vendor with meagre earnings. He had taken a loan from moneylenders, at high interest, to meet the expenses of the

treatment. Wajiha's family expressed the distress they felt at being unable to afford the cost of the procedure. They were devastated and distraught.

The accident rendered the family even more vulnerable. Their daughter's trauma had devastating consequences. Wajiha could become incapacitated. The accident was a public health problem arising from the incredibly poor housing situation. Was this accident preventable? Could her home have been made safer and the environment improved? Fate had willed otherwise.

The scar of this accident was felt by the whole family. So much suffering and pain could have been prevented. The effects of the accident could last throughout Wajiha's life. Being poor she was already compromised by poverty and marginalization. Her mother, who had kept a round-the-clock vigil, said that for her little girl to be so cruelly snatched from health at such a young age was absolutely devastating.

Heartfile covered the cost of Wajiha's treatment.

PARMIN GUL - A WIDOW FROM MOHMAND AGENCY



Life had not turned out the way Parmin had wished. She was married off at the tender age of fifteen, bore two children and was a widow at 22. Her whole world was torn apart. She had been brought up on the ideals of motherhood and the sanctity of marriage. Widowhood had a brutal and irrevocable impact on her and her two young children.

"As soon as my husband died, without any treatment for his cancer, my in-laws took everything away. I had been married for seven years. My children and I were evicted and cast off. I lost all, my sanctuary, my refuge, my house and home. I had no choice but to return to my old father's house." Parmin returned to the comfort of the home in which she had grown up. Her father and brother, both migrant, unskilled workers from Afghanistan, offered her solace and the moral support she needed to move on in life.

She said that she would probably spend a long period of her life in the state of widowhood with all its disadvantages and stigma. She was from a small village, Derai Bazar, on the border of Mohmand Agency. In Mohmand Agency as in most traditional communities, widowhood represents social death for women.

Parmin, in the prime of her youth, sat on her bed with a sad look which reflected grief, loss and ill-health. She had been consigned to the very margin of society where she was suffering from extreme forms of discrimination and humiliation.

Parmin arrived at Lady Reading Hospital with pus being discharged from a wound caused by an earlier chest intubation: she had developed pneumonia which led to pleural effusion. The pneumothorax, which is an abnormal collection of air or gas in the pleural space separating the lung from the chest wall, interfered with her breathing. She could not bear the acute chest pain and shortness of breath. She was immediately admitted to the Lady Reading Thoracic ward for a decortication. The cost of her operation was paid for by Heartfile.

Parmin suffered from general ill-health and malnutrition and lacked the means to obtain appropriate forms of support. Her grief over the loss of her husband and companion led her to suffer deep sadness, as well as financial problems in the wake of her own ill-health. Ill-health and stress resulted in her developing chronic depression. Poverty for her was the loss not only of her income but also of her total well-being, her peace of mind and health. She felt as if she was a liability to her old father. She added that she would continue to endure extreme poverty, ostracism, ill-health and discrimination because of law, custom and tradition. The family was so poor that they could not afford to send the four children in the family to school.

Parmin was aware that she would remain poor and unprotected by the law because her life would be determined by the local patriarchal interpretation of tradition, custom and religion. As long as her father was alive, she would be under his protection. Once he died, she would be in limbo. This case shares the two common experiences with other widows across the globe: a loss of status and reduced economic circumstances. Her dream of a

peaceful life had been shattered. Although she found it difficult to handle the loneliness and the despair that come with the feeling of being rejected, she struggled to regain her health to be able to take care of her small children.

Parmin belongs to the poorest and most vulnerable of social groups, apart from having the stigma of being a widow. Parmin will likely end up as another invisible woman, secluded and excluded. She has been pushed to the very margins of society, trapped in poverty and vulnerable to abuse and exploitation. These are the dire consequences faced by widows. They are forced to live in devastating poverty and ill-health only aggravates their situation.

NOOR BEGUM - MARGINALIZED WITH A UTERINE MASS

A hysterectomy is a surgical procedure to remove a woman's uterus. Noor had been diagnosed with uterine cancer. A radical hysterectomy was deemed necessary in her case; it involved the removal of the whole uterus, tissue on the sides of the uterus, the cervix and the top part of the vagina, on account of the spread of the cancer.

The procedure consisted of an open surgery which involved a five to seven-inch incision from side to side across the belly. The surgeon removed the uterus through the incision. On average, a woman spends more than three days in the hospital following an abdominal hysterectomy. There is also, after healing, a visible scar at the location of the incision.

Noor had abdominal pain for over one year with a rapid increase in the intensity of the pain over recent months. With the passing months she had become increasingly sick. Her weight plummeted to a frightening low and she could not eat. She had also developed associated lower abdominal pain. She became more concerned when she started having post-menopausal, heavy vaginal bleeding.

Painfully thin, weak and unable to walk, she was rushed by her sister to the hospital. She was quickly diagnosed with uterine cancer. Uterine cancer arises from the lining of the uterus (the endometrial). Most cases of uterine cancer develop in women in their fifties or sixties. Noor was fifty-six.

According to a survey by the Information Centre, SteadyHealth.com, uterine cancer is the fourth most common cancer diagnosed in women. The data shows that uterine cancer can affect any woman but there are some who are more prone to it than others, such as white women. It was also found that the women who are least affected by uterine cancer are those living in Southeast Asia and India.

Noor had never had a baby. This could be another cause of the disease as the womb would never have had a rest from the increase of estrogen that happens in the course of the normal monthly cycle. She started periods at a young age and had a late menopause after the age of 52. She was 56 when she was diagnosed with cancer. All these factors: age, period cycle, menopause age and not having been pregnant, were likely to have contributed to the risk of developing cancer.

Noor lived with her elderly mother in a small mud house without electricity, running water or gas. Her spouse was a migrant worker in the city. Three years earlier, she had been diagnosed with a heart condition and was advised that she needed an endoscopy and likely surgery. However, she had to forgo treatment as she could not afford the cost of the procedures. She was faced with the plight of being deprived of medical facilities simply because she could not afford to pay for an urgent surgical intervention.

Little attention is paid to the immediate need of people such as Noor – affordable and decent medical care does not exist in Pakistan. She did not go for treatment of her heart condition due to the cost. The fact that she was unable to pay was amplified by the uncertainty of recovery. Thus, she excluded herself from treatment and only came back for medical care when her health problems became even more serious.

Noor said that her life had been limited to housework and agricultural labour. Her contributions had always remained invisible. Noor said "I have been enslaved by my crushing daily burden, by depression, fear and poverty. Now, with the anxiety of ill-health added to all these, I cannot take it anymore." Survival had been a constant struggle for Noor. Basic amenities such as food, water, fuel and health facilities had been lacking throughout her life. Simply surviving to her present age had been Noor's greatest challenge. She had spent her whole life trying to overcome a series of poverty-caused obstacles along her path.

Besides the disease, she said that she carried the disgrace of being childless. In Pakistan infertility is seen as a personal failing, or even a curse: a woman who cannot conceive often faces devastating isolation. Noor remembered having suffered from the stigma of being

unable to bear children. The consequences of infertility for her included ostracism and verbal abuse.

Among uneducated women, their only identity comes from being mothers. Childlessness had been the cause of profound suffering for Noor. She mentioned that people never wanted her around during joyous occasions because she was considered to bring bad luck. Women generally take the blame for childlessness, even when the problem lies with the man. They are forced to keep their spouse's secret and bear the insults themselves.

Noor's case was referred to Heartfile through an emergency call at a weekend. The surgery had to be performed immediately and the sum could not be raised by her family. Heartfile's response was instant and the case was processed and approved in the record time of four hours. Thus, her treatment was financially supported. It was an instance when the team at Heartfile came together to respond to the call of a poor, needy patient whose life was in imminent danger from the disease itself and the heavy bleeding caused by it. This demonstrated the efficiency, dedication and commitment of Heartfile to its voiceless poor patients.

Noor was operated upon, yet she remained uncertain because of the likelihood that the disease might recur. She was not aware of the extent of the disease or of the projected success of the treatment. She was left greatly distressed, without any reassurance from the doctors. She went back to her village to live with this uncertainty. Her fears would not lessen and it would be difficult and very stressful to continue her existence there. The disease, combined with severe poverty, had its own type of deep uncertainty.

Not every problem can be solved with a scalpel.

SAKINA BIBI - DESTITUTE

Sakina Bibi, an old lady of seventy-eight, lived in extreme poverty. Her old age was by no means golden. She had survived her husband but had no income and lived impoverished with two disabled, adult children – a son and a daughter-in-law, both deaf and dumb and two normal grandchildren. She was destitute, living off the charity of her neighbours and of the wider community. This poverty-stricken widow lay distressed and in rags on a hospital bed. She had a fractured tibia and a compression fracture of her left leg. She had fallen down a flight of stairs.

Sakina was left unattended for eight days until a neighbour came across this clearly destitute old woman with a badly broken leg. It was clear that, if left unattended, she would not last long. Taking pity on the old lady, he offered to take her to the hospital. The neighbour was attending to Sakina out of simple compassion, without any self-interest. As the old lady said to him, "You are indeed a man of great kindness. I can see it in the deep black of your eyes." With the warmest of intentions in his heart, the neighbour had taken time off work, had the old lady admitted to the Pakistan Institute of Medical Sciences and had been attending to her for the past eight days.

This was an act of kindness and philanthropy. Pakistan is considered among the most charitable nations in the world. It saw the 'largest jump in ranking in philanthropy globally of 108 places, moving from 142nd to 34th in 2011 according to the World Giving index 2011'.

Sakina Bibi was a person who, in spite of her old age, took care of her four dependents. The old lady was noted for her efforts, devotion and the care of her family. Her son got married and she felt happy, she said, to have a new member in her family. She added that this happiness was in vain. She was dejected, fell silent and cried as she said that she had nobody to care for her except her neighbour. She said during the accident her feet had collapsed and darkness had clouded her eyes. She felt that she had reached the end of her life. Tears flowed down her face. Sakina did not seek medical help because she could not afford to see

a doctor. Her finances could not meet any medical cost. Her family was already heavily in debt and crushed by poverty.

"For me it has been a lifetime of caring for my disabled son. Now, with the accident, I have reached a stage where I cannot do this much longer. I had insisted for a place for my son in society rather than on the fringes. I got him married to an equally disabled woman, so they could be compatible; I provided him with a skill as a tailor. I have raised him without any support and he has remained a person with special needs. He worked for a number of years but is now severely disabled with arthritis."

On account of her inability to pay for treatment and having no source of income and relying on the generosity of the community, Sakina Bibi's case presented strong justification to be supported by Heartfile. A package was approved for an interlocking nail to repair her leg. Closed interlocking nailing was the procedure of choice for the fracture of the femur and is a common method of treating fractures of the tibia and femur. It offers reduced risks of infection and decreased risks of shortening or rotation.

The case reflects the impact of gender roles on the cultivation of social networks and how these networks in turn impact on needs; how an old woman had adjusted and coped with the challenges of disability in her adult children and how philanthropy came back to her life. The key issues are gender, disability, health, aging, poverty and philanthropy.

Poverty, widowhood and old age predisposed Sakina Bibi to the risk of accident and made her and her disabled dependents vulnerable. A worsening of already acute poverty was caused by the accident. She was more vulnerable for several reasons, including lack of access to health services.

It is hard to look at such vulnerability and suffering, so most of us do not; we pass by, in denial. Though she spent her life helping others, Sakina Bibi was herself deprived of the minimum social safety net. At Heartfile we feel privileged to be able to help people like her.

GULZAR BEGUM – THE FEMALE HEAD OF A HOUSEHOLD

The odds of getting hurt on a motorcycle are much higher than those of being in a car. Such injuries are often life-threatening. Gulzar Begum, a 40-year-old woman, suffered a broken elbow after she was thrown from the motorcycle on which she was riding. She was not wearing a helmet or any protective clothing when the accident took place. She was riding with her younger brother who apparently was moving at an irresponsibly fast speed. Bolts of intense pain shot down her arm. Her arm quickly became swollen and turned black and blue. She was in agony. She lived in a distant village in the Punjab rural region and was taken to the local doctor for treatment.

“I was in a lot of pain and my elbow was out of shape. I was unable to bend my arm,” she said. “I had shattered it. Finally, I was taken to Benazir Bhutto Hospital in Rawalpindi.”

The X-ray revealed a fracture in the elbow and she was told that she would need surgery to repair the break. Being the female head of a household, the only earning family member, with six minor dependents and a disabled spouse, she could not meet the cost quoted for the surgery from her small daily wage. Her spouse had suffered an attack of paralysis ten years ago and become completely disabled. She travelled daily to a vegetable farm to do the backbreaking chores of a manual labourer. She belonged to a poor family from a village where the sources of income came only from agriculture and other manual work. She was illiterate with no skills and all the members of her family were dependent on her income.

She described her daily life: “I get up early in the morning to bring water from a nearby well. I leave the children to do the housework. Then I travel to the farm every day of the week and spend the whole day either sowing seeds, planting seedlings, tilling the land or watering the plants. As an illiterate woman without skills I cannot aspire to a better job. The hot weather makes the work environment unbearable. I am relegated to strenuous manual labour. Mine is all manual work – women are often denied access to the machinery because the men take the easier jobs for themselves. So, though we are less strong than the men, we

have to work far harder than they do. I have no choice but to work hard to provide for the family.”

Gulzar Begum’s face clouded up while she described her terrible ordeal. “I am becoming an invalid,” she said, her eyes moistening with tears. “Do I have any chance of recovery? Do I just have to live with disability? I have lost all hope. I have a lot of life to live and I must care for my family and my children.”

Nobody was around to sit down with her and calm her fears. Her fracture had resulted in problems with movement, blood vessels and nerve function. The break involved the three arm bones which work together to form the flexible elbow joint. Heartfile provided the money needed for a procedure for the fixing of the humerus (the bone in the arm) by means of a metal plate. Plating has been shown to have better results compared to interlocking nails in the treatment of these shaft fractures. There is a tendency for an earlier union of the bones and hence a fuller recovery, when plating is used.

Lack of resources and poverty led Gulzar Begum to a situation of increased vulnerability. She had no informal social support. She alone led and managed the household. She was not only poor but also a victim of prejudice of customs and beliefs and had been struggling against the patriarchal dominance of a traditional and conservative society. She was triply disadvantaged by the burden of poverty, gender discrimination and lack of social support. Being the main wage earner, the accident meant she fell deeper into the poverty trap. Thus, she experienced multi-dimensional poverty arising from being the female head of the household and from the absence of any support network.

Gulzar Begum feared she would not fully recover, which would mean total loss of income and the inability to support her children and care for them. Her daughter said that her mother was an amazing woman who had truly led the family through moments of great adversity. She said her mother was a much stronger woman than she had ever realized. Although Gulzar Begum mentioned that her world had turned upside down, she tried to show resilience for her family’s sake by putting on a brave face. Elbow injuries are common in both adults and children. Early recognition and treatment of an elbow injury can reduce the risk of complications and later disability. Gulzar Begum was lucky to have been

attended, treated and supported financially in spite of the complications of the injury. She left the print of a remarkable, resilient and courageous head of a household. Her willingness and will power to be cured would prevail. The story depicts the gender disparity of a woman at all levels in the work force. From the start, gender-based divisions of labour dictate and limit women's tasks. When the contribution of wives and daughters become vital for survival, the harsh conditions and suffering caused by the hard manual labour to which they are relegated must be endured. The dilemma caused by an accident can then bring life to a standstill and the future much into question.

SHAMSHAD – A CASE OF RETROSTERNAL GOITER

Shamshad's priority, like many women, was taking care of her family and the household. She sat on her hospital bed waiting to be listened to as she had a tale of pain and endurance. She showed all symptoms of a thyroid dysfunction, with an unusually swollen neck and bloated face.

Five years ago, she had been seen by a doctor and diagnosed with the condition of a retrosternal goiter. During these five years the goiter remained silent; she had no follow-up treatment but would occasionally take the medicine prescribed when she could afford it.

Her condition deteriorated to the extent that she was hospitalized in the cardiothoracic unit of Lady Reading Hospital in Peshawar. Her thoracic function was deranged and extended into the thoracic cavity and had caused an enlarged goiter. Normally, a retrosternal goiter occurs when the thyroid (which is meant to be in the neck) enlarges downwards into the chest. Shamshad's case was an extension from the neck and was left-sided.

The goiter had slowly but relentlessly grown in size over the past five years. She stated that she constantly had a feeling of pressure and had trouble swallowing or breathing. The possibility of a biopsy was eliminated as it was a difficult and almost impossible procedure. In her case, the required procedure was to reduce the need for a secondary surgery due to regrowth of retained thyroid.

The five years of neglect showed a relentless increase, with visible swelling of the neck and face. Surgery would reveal if there was malignancy. Such a condition of retrosternal goiter occurs in seventy-year-olds as studies have shown and it is a rare case for a thirty-year-old to suffer from this condition.

Shamshad was a mother of four children; she had to care for a sick spouse and a mother-in-law with a heart condition. Her spouse did not work and the family of seven depended on the small income of a young son for survival. She was already in debt and could not afford

to send her children to school and so opted to send them to a free religious institution. Thus, the children were denied a formal education. She stated that she did not consider her health a priority until she became very sick and was unable to bear the burden of a caregiver. Her CT scan confirmed a mass which might harbour cancer. Her chest X-ray showed a large retrosternal goiter which was compressing the trachea and displacing it to the right.

According to some studies the definition of retrosternal or intrathoracic goiter is not clearly agreed upon. Medically, as per certain schools of thought, it is not agreed that a goiter is retrosternal if this greater mass is inferior to the thoracic inlet. A suspicion of malignancy led to the option of a total thyroidectomy for which Shamshad had been referred.

It is to be noted that there are two schools of thought – the conservative surgical groups argue that the incidence of cancer is no higher than cervical goiter and that there should be no indication for surgery; the aggressive surgical groups argue that a retrosternal goiter should be operated on towards an attempted cure and thus prevent the dreaded complications.

Shamshad was referred to a team of thoracic surgeons who had significant experience of retrosternal goiters and she underwent a successful procedure which would prevent further complication or carcinoma, which would have necessitated mediastinal dissection. Heartfile supported the cost of the procedure.

Neglect, poverty and lack of caring for herself led to Shamshad's deterioration. Could no-one in the family be prevailed upon for her to be treated or was it because she was a woman that her health was not given priority? Would she be offered post-operative treatment and follow-up, or would she immediately take on her previous responsibilities as care provider? Shamshad's is a story about the trials and tribulations in the life of a woman.

KHAISTA BIBI – A CASE OF CERVICAL RIBS

Khaista Bibi, a 36-year-old woman, was born with two extra cervical ribs. Chest and neck X-rays discovered the condition. A cervical rib normally appears on one side, though occasionally a person may have one on each side. It is a congenital condition, meaning it is present at birth. Cervical ribs are an anomaly that grow from the lowest cervical vertebrae (the seventh vertebrae) and are located above the normal ribs. A cervical rib is present in about 1 in 500 people. Almost all mammals have seven cervical vertebrae.

It is extremely rare that an individual has two extra cervical ribs. They are sometimes known as 'neck ribs' (Salim Jocelyn, *Useless Body Parts*). This condition appears more frequently in women than in men and it exists usually without symptoms. The problems arise when the rib places pressure against the blood vessels or the muscles running through the neck into the arm.

Khaista Bibi was unaware of the condition until she turned twenty. Her symptoms started with progressive pain in the neck, shoulder and back, with numbness in her arms. The aches increased gradually over the years. She was occasionally taken to the doctors in the village. She was only prescribed pain killers, without any exploration and these doctors were unable to diagnose the ailment. Her chronic and persistent pain, her weakness and loss of ability to use her arms alarmed the family. She was brought to Lady Reading Hospital where she was diagnosed with cervical ribs. A rib resection was determined as a solution; this is a procedure to remove the extra rib. Surgical removal of clavicle ribs began in the early 1990s but this difficult procedure often resulted in nerve and vascular damage. In recent decades rib resections have become safer and more successful with the introduction of endoscopic surgical procedures that use a computer-assisted video to make small incisions. Surgical intervention helps where there is obvious physical evidence.

Khaista underwent a rib resection and the first rib was successfully removed. Another surgery was recommended for the removal of the second rib after three months of recuperation. She did not return as advised because the family could not raise any more

money within the suggested period. They had to first pay back the loan taken for the first surgery. Poverty, combined with a lack of cervical rib awareness and access to the proper medical care, delayed the follow up surgery and treatment. Ten months later she was again rushed to the hospital in excruciating pain. Again, she and her brother, her attendant and escort, travelled hundreds of miles to Karachi Port Trust Hospital. The trip was made by changing several public vehicles and passing through areas under curfew. The relocation for treatment entailed the cost of transport for the patient and her brother, their stay and the cost of prescribed medicines, in addition to the loss of family income.

Khaista has only one brother and he was a daily wage earner who had to abandon his work to accompany her and attend to her during her hospitalization. The cost of treatment was not affordable for a family of twelve dependents living under the poverty line. Furthermore, they were homeless with the shelter of only one room without the basic amenities of water and sanitation. They fetched water from neighbours, used the neighbours' dry raised latrine and had no kitchen. All these are clear indicators of severe poverty. A request was made to Heartfile to support the intervention and the amount was immediately approved for the cervical rib fixation.

Khaista expressed feelings of depression, loneliness, anxiety and fear. Her health was neglected because she paid no attention to her own well-being. Her physical health had never been robust, she said and her mental state was much affected. The chronic ill-health she was experiencing had damaged her self-esteem. It had eroded, she added, her sense of respect and self-worth. Her body image and social relationships were undermined by the fact that she was always unwell and could not contribute to her family's struggles.

She was very much aware of how the burden of her sickness affected the family as it had totally disrupted their daily routine. She mentioned that she was constantly haunted by being single and the likelihood of remaining single for the rest of her life. Being unmarried and sick, she was almost invisible. She said that her thoughts and feelings were rarely taken into account. She was economically weak and vulnerable on account of the social stigma attached to her unmarried status. She had silently accepted her fate. Her being 'unmarried and sick' was a great point of anxiety for Khaista's brother. He said that he kept this worry

to himself and was unwilling to share these concerns. He also feared that this stigma would be with his sister for life, to her grave.

Khaista's case depicted a sad story of a life marred by multiple issues. She was trapped by poverty, was conditioned by traditions with their attached stigma, belonged to a very conservative region where women are treated more as commodities than people and foremost, she suffered from a rare ailment that could be cured but only at the cost of specialized and expensive treatment. She indeed had a complex and hard existence, with little hope of a positive future. We are privileged to be able to come to the rescue of people like her.

LAIBA BIBI – A GIRL CHILD



Laiba Bibi had travelled to Peshawar all the way from Lakki Marwat in the northern part of Khyber Paktoonkhwa between the Bannu and Dera Ismail Khan Districts. The area was infested with Taliban miscreants, a stronghold of Pakistani Taliban. Lakki Marwat is an underdeveloped and poverty-stricken region of Pakistan known for its resistance to governmental authority and military control. The journey was unsafe, but her parents were determined to seek treatment for their daughter after years of suffering. She changed several buses before reaching Lady Reading Hospital in Peshawar.

Laiba was three and a half years old. She was admitted with a thirty-six-hour history of acute abdominal and shoulder pain. She subsequently developed a cough and vomited on three occasions. Additionally, she had severe breathing difficulties, bluish coloured skin, due to lack of oxygen, rapid breathing and an accelerated heartbeat. Initially the diagnosis was of pneumonia with abscess formation. Later, further examination, exploration and X-rays revealed a congenital diaphragmatic herniation involving the abdominal organs on the left side of her chest cavity.

A diaphragmatic hernia is a birth defect in which there is an abnormal opening in the diaphragm, the muscle that helps us breathe and separates the chest from the abdomen. This abnormal opening allows part of the organs from the abdomen (stomach, spleen, liver and intestines) to move up into the chest near the lungs. The diaphragmatic hernia is caused by the improper joining of structures during foetal development. As a result, the abdominal organs are actually in the chest cavity. The lung tissue on the affected side is thus not allowed to completely develop. This condition is seen in one out of every 2,200 to 5,000 births. Most are affected on the left side. Having a parent or sibling with this condition slightly increases the risk of its occurrence.

Laiba's case demanded urgent treatment as her symptoms continued to worsen. The surgery involved the placing of the abdominal organs in the proper position and repairing the opening in her diaphragm. The greatest challenge for the family was that their financial resources were inadequate for the treatment. Heartfile supported them.

The severity and depth of the family's poverty was revealed in the absence of any earlier treatment. The main responsibility for Laiba's care lay with her mother. Being a girl, was she adequately taken care of? Did the mother have the capacity or resolve to care for her and to ensure Laiba's health and well-being? Laiba had been sick since birth. A son was born after Laiba and all the family's focus and resources were transferred to him, typical of their society, where the males are considered of much more importance than females. Social and gender discrimination was obviously one of the factors that caused the delayed treatment.

Laiba was born into poverty; even her young gaze, the depth of her expression, reflected perpetual pain. Her weak frame could hardly support her. The family was already experiencing chronic poverty. Both parents expressed feelings of distress. The father stated that their inescapable poverty and the ill-health of his daughter had negatively affected his life and hopes. He felt discouraged about her survival and this caused despair. For the family, life had been a harsh experience which continually created obstacles for accessing health care. The family had always been destitute and felt that it would be extremely difficult to climb out of these privations.

Surgical repair was the only treatment for Laiba's condition. The family was informed that the outcome would only be successful with aggressive post-operative care management. The family could not afford to remain close to the hospital and its medical care; unfortunately, the possibility of any close post-operative observation and therapy had to be dismissed. This posed a great challenge since the financial constraints and the family's residence being so far from a tertiary care hospital, precluded Laiba from obtaining the necessary follow-up treatment. In Laiba's case there was the risk of post-operation lung infection and that would mean the end of her short life. Based on insights from such cases, Heartfile has now introduced a new program to financially support families from far flung areas to stay in town while their loved ones are being treated. Many are benefitting from this.

ZULIKHA – A SIXTEEN-YEAR-OLD TUBERCULOSIS PATIENT

The girl who was ill was undeniably beautiful, with a smooth tanned complexion, dark brown eyes and dark brown hair. She wore dozens of bangles. The hope was that she would live to see another autumn. She was only sixteen years old, young and with a life that seemed full of promise but ill-health began to take a heavy toll on her. She had been diagnosed with tuberculosis four years ago.

Tuberculosis has always been prevalent in Pakistan and unfortunately, it has been a neglected area in the past. Pakistan ranks sixth in the world among the countries with the highest burden of tuberculosis. According to the World Health Organization, the incidence of sputum-positive tuberculosis cases in Pakistan are 80/100,000 per year and for all types it is 177/100,000. Tuberculosis is responsible for 5.1 per cent of the total national disease burden in Pakistan. Thus, the impact of tuberculosis on the socio-economic status is substantial. Also, sadly, this is one of the most preventable diseases that afflict children in poverty.

Tuberculosis is a highly contagious, air-borne disease. According to the Centre for Disease Control, "The tuberculosis bacteria are released into the air when a person with active tuberculosis disease of the lungs or throat coughs, sneezes, speaks or sings." It spreads easily and quickly in lower-income areas where people have generally weakened immune systems. However, only people with the active tuberculosis disease can pass it along to others. If tuberculosis goes untreated it can be fatal. Though fewer women than men suffer from tuberculosis, women are at a disadvantage since detection and treatment of disease are low priorities for females in Pakistani society. They are also more likely to suffer from general poor health and lack of proper nutrition.

Zulikha was underweight and weak, had a persistent cough bringing up bloody sputum and was unable to sit up for very long. She looked extremely malnourished and anaemic. She had become dependent on her mother to do everything for her. She and her mother had

managed to navigate a weak medical system and had overcome numerous hurdles in order to get some medical care, but Zulikha was unable to seek serious treatment. This time she was back in the hospital with one lung collapsed and the other infected. The disease had slowly taken over her body and was affecting her mind. She and her mother lived in a state of constant fear and anxiety. She wondered whether her fate was sealed, whether she was condemned to die. The incurable cough of death began initially as just a cold.

Zulikha lived in urban poverty in one rented, dark, unventilated room, without access to clean water or sanitation, which rendered her even more vulnerable to the diseases of the poor. Furthermore, her resistance to the disease was reduced by malnutrition. The presence of a tuberculosis patient in the family had entailed a major re-allocation of time towards her care and the mother had missed work attending to her in hospital. Thus, it meant reduced family income – pushing the family further into abject poverty and marginalization.

In her life Zulikha had known nothing but ill-health and poverty with her mother and younger brother. Her present tragedy was further complicated in that she had never known her father, who abandoned her mother for another woman and disappeared from their lives with no explanation. Zulikha said that it was a devastating experience and something that would live with her for the rest of her life. She added that his was an absence at a time when she needed a father's support most. This was a bond which unfortunately had been broken forever. The family depended entirely on the single mother, who was left to raise two young children and play the role of both mother and father. She had a very difficult time raising the children alone and earning enough money to support them. She was a home-based craftswoman who was exploited by a middleman for the work she produced. Thus, Zulikha remained poor, oppressed, illiterate and uninformed, as well as anaemic and in poor health.

All of these socio-economic factors contributed to ill-health and were augmented by poor nutrition and hygiene, poor living conditions and lack of access to medical facilities and medicines. The family lacked a proper diet and the mother mentioned that there was never sufficient food in the house. It was obvious that malnutrition had had permanent damaging effects on Zulaikha's body and likely on her mother and brother as well.

Zulikha's mother bore the primary responsibility for her daughter's treatment. Looking through the lens of hunger and poverty, there were numerous areas of discrimination against this female child patient – malnutrition, poor health, educational deprivation, and overwork. Zulikha was unskilled and suffered mistreatment from all levels of society. She was powerless to improve her life and chronic hunger with abject poverty added to her desperate situation. Her mother referred to the social stigma attached to the reality of the disease itself. She was afraid that neighbours and others would learn of her illness. The fear was that if people knew her daughter had tuberculosis it would be impossible to find anyone who would marry her. This stigmatization was as frightening as the disease itself. The intangible cost resulted in depression and anxiety and added to the burden of the tuberculosis itself.

Our hearts went out to this mother and daughter. Heartfile came in to support the financial cost of Zulikha's procedure - but had she already been given an 'expiry date'? This was a case where the patient could not access timely treatment and was disheartened by her financial situation. An early detection of the disease and treatment would have saved her from all this pain and suffering. Now it had become a challenge for survival. Tuberculosis affected Zulikha during her most productive period of life and hampered her ability to break free of poverty. As Archbishop Desmond Tutu stated: 'Tuberculosis is the child of poverty – also its parent and provider.'

YASIR – WITH A DRUG-ADDICTED FATHER

While talking to Yasir I was captured by a powerful story. His eyes carried so much emotion and deep sadness. They reflected the pain and suffering that he had endured physically and psychologically.

Yasir had a two-month history of low-grade fever, cough, shortness of breath and weight loss. He had sought private treatment and was put on anti-tuberculosis treatment prior to his admission to Lady Reading Hospital, Peshawar, where he was diagnosed with a tuberculous empyema. Tuberculous empyema is common in a country like Pakistan. His disease was further confirmed through radiological evidence of active pulmonary tuberculosis in a chest X-ray. He was expected to undergo decortications at an estimated high cost. Heartfile came in with the financial support for the procedure.

Yasir looked pale, dehydrated and lean. He was twenty years old, the only son and eldest child of his parents. He was pulled out of school at the age of twelve and sent off to work. He had to support a family of seven as his father was a drug-addict and was unemployed. Forced to assume the role of a parent, Yasir grew up fast. He felt responsible for his parents' problems. His mother was at his bedside and suffered her only son's sickness, as well as deprivation and abuse from her drug-addicted spouse. She stated that Yasir was carrying her hopes and that of his siblings. Their hopes rested on his shoulders and that was a huge weight.

Yasir had had a turbulent childhood, throughout which he had undergone tremendous emotional burdens and carried an unbearable weight, trying to take care of and protect his mother and four minor sisters from the abuse of an addict father. In the process of enduring so many hardships, he said, he had lost his childhood. Relations with his father since childhood had been very difficult and deeply damaging for this still very young man. The psychological toll of his illness, of poverty, of the abuse and drug addiction of his father had extended to the whole family, impacting home life and future choices for those living under the same roof as this abusive man.

The family resided in a deprived area on the outskirts of Peshawar, in a dilapidated ancestral home, under a roof that leaked, with falling mud walls and with monthly utilities to pay. Yasir was the sole earner with a meagre salary of Rs.7000. The family depended on food handouts from relatives and the community. He was compelled to incur a loan of Rs.16,000 to meet his own medical expenses and this amount was already spent. He worried about how he would pay back the loan, fearing he would be further in debt. The family was without any asset and under the burden of a loan which had been taken for their subsistence. Yasir was unable to work and thus the family was deprived of his monthly income. The duress of the ailment, the crisis caused by poverty, as well as the emotional and psychological scar, drained him.

He said, "Time goes by so slowly here. It just drags. I do not know how to describe it. It is almost as if it stands still. It is a terrible, terrible situation to be in but there has to be hope, and you have to stay hopeful." He added that he wanted to get well and be able to care for his mother and sisters again; he alone bore all the responsibility of doing this as the only male and eldest child.

Yasir underwent the decortications and the cost was supported by Heartfile. He was in a hurry to go back home and resume work. He did not realize or was not told about the importance of follow-up treatment for a period of six months to ensure complete cure and no recurrence of his disease. The communication generally between patient and doctor is minimal: the post-operative care briefing is left to the nursing staff who in many cases neglect doing so because they are too busy and overloaded with attending to other patients.

FAZLUL REHMAN – FATHER OF A DESTITUTE KIDNEY PATIENT



Fazlul Rehman, father of Mohammad Saeed, knocked at the gate of Heartfile in despair, on a Friday morning, after being lost in the turns and twists of hospital passages. His son Mohammad, twenty-seven years old, married with a young wife and a small child, was shocked three months earlier, when he was told that his kidneys would no longer sustain him. The kidney disease must have been advanced as he collapsed and now could not even work as a labourer and painter. The patient's journey of struggle had started.

He was taken for dialysis by his father to the Pakistan Institute of Medical Science in Islamabad where the endless queue discouraged them after three sessions costing Rs.4000. In the hope of finding cheaper sessions they changed centres and doctors, trying their luck

at Lady Reading Hospital in Peshawar, where Mohammad had dialysis three times at a cost of Rs.3000. He returned to the hospital but there were 15 people ahead of him in the queue. The father decided to take him to a private hospital where the treating nephrologist at the hospital had his private practice. The father had to pay Rs.9000 in the private hospital and unable to afford this, he was advised to go back to the Government hospital, where, he said it was almost impossible to get access to the nephrologist.

Fazlul Rehman was a 24-hour guard; he earned a small salary and had sold his ancestral inheritance in a village near Mardan. Furthermore, he sold his wife's jewellery and the furniture of the house to meet the initial cost of the treatment. He later borrowed Rs. 30,000 from various relatives and had a pending bill of Rs.12,000 at the chemist. Burdened by debts and a family of 15, he said he was unable to cope with the situation.

He said that his dignity would not allow him to extend a hand for charity but requested that Heartfile speak to the nephrologist so that he would attend to his son. He could not conceal his anxiety of the future financial cost and his pre-existing debts.

“You would understand the pain of a parent witnessing his young child suffering and dying slowly,” he said. “I have nothing; I am completely devoid of hope.”

The nephrologist, who was out of the country suggested that the only way to slow the course of the chronic kidney disease was to have a transplant which would cost Rs. 300,000. The father thought that this might be the illness's last stage and that death was near. He volunteered to be the donor and waited for a tissue match but again, he reiterated, the doctor in the hospital was inaccessible.

This disease could be treated successfully but for such a poor patient like Mohammad Saeed the costs were impossible to bear as the father had already incurred high expenses and borrowed money from many people. This was a life-changing decision for him – the father of seventy-six had offered to be the donor.

Mohammad Saeed chose the option of dialysis in the beginning. It was expensive. The transplant, he said, is a ‘distant dream’ that may come true at great risk to his father’s health.

Fazlul Rehman had decided to donate his own kidney to his imperilled son. This father was filled with compassion, gentleness and a deep, loving concern for his son.

This narrative cannot truly describe the distress and helplessness of a father with a sick son. It has seen intense moments of suffering and poverty. They were such desperate moments and reflected the dire need for better health care in this country. During our face to face conversation I stopped for a moment to conceal my tears. It was such a moment that I felt I should continue to record the pain of this father, the strain on him of deprivation and poverty. At the same time there was a moment of calm. In the eyes of this religious father, is the closest I have been to something spiritual.

Documenting this story felt important and I have been honoured to do it. I felt so privileged to relay to the father, on Heartfile's behalf, that his son's case for a kidney transplant had been approved for funding.

The realities and consequences of poverty, illness, marginalization and exclusion are vividly spelt out through this narrative. The connection with the distressed father filled me with confidence in the spirit of humanity. I grew incredibly close to this father and for a long time it made me want to give up everything. It seems that we have forgotten the world of people who live on the margins of society.

NOOR MOHAMMAD - MARGINALIZED



His eyes had the intensity of someone who has been totally drained by anguish, pain, anxiety and poverty. Noor Mohammad was a 49-year-old outpatient who had been commuting from a village near Mianwalli to Islamabad for the past year and a half. When we met, he made a desperate call for help. What was unique in his case was the absence of any mask to cover the reality. He was disheartened, disillusioned and seemed resigned to his situation. He was too distressed by pain to be able to communicate with us.

He was very hard of hearing, so we sat by him in the waiting space of the outpatient gastroenterology section in order to hear of his plight, which he described with

great difficulty. He had been attending the local government hospital in Mianwalli and when he lost consciousness, he found himself transported to the Pakistan Institute of Medical Science in Islamabad. The wait for medical attention was lengthy and he had even tried private treatment but could not afford to continue with it and so he returned to PIMS.

He complained of dysphagia, difficulty in swallowing, both solids and liquids. Tests showed a narrowing of his oesophagus. A CT (computed tomography) scan revealed a malignant stricture. It was decided that he was a candidate for oesophageal balloon dilation (opening up of the food pipe by putting a balloon in the food pipe). An expandable stent placement would be safe for him and it was hoped, would be effective.

He said that he had made at least 30 trips to Islamabad and had taken on heavy loans from different people. His case came to the attention of the treating doctor and Noor Mohammad was referred to Heartfile for financial support, which was given. Multiple hospitalizations, as well as the instability of his condition had made it impossible for him to go back to work and greatly worsened the economic condition of his family.

Noor Mohammad was an unskilled worker with a large family, whose only asset was a buffalo providing milk to the family. He had been thinking of selling the buffalo to be able to pay for his treatment but luckily Heartfile stepped in. He lived in a thatched hut without electricity, gas or running water. The family fetched water from the common water pump of the area.

The pain and back-breaking effort of bringing the water were obvious. Whenever he felt a little better, he went back to work as a labourer. He had been compelled to pull his 14-year-old son out of school so that he could add to his father's meagre labourer's income. He constantly had difficulty in managing his life effectively due to his prolonged illness.

Noor Mohammad said that he had always experienced this pain, that it was a daily constant and that this plea was coming from his heart. He wore the look of a desperate man who had been fighting for a long time and yet continued to display a willingness to go on fighting his disease. His story was tragically clear. For him, access to medical care had

become a vital necessity. He had to continue living to support his family in spite of facing numerous social disadvantages, extreme poverty and poor nutrition.

The only refuge, to which he had access in Islamabad, was the veranda of a hotel. He desperately pleaded that he could no longer spend the cold winter nights without shelter and that he could not pay for any accommodation. He said that having nowhere to stay in an unknown city was frightening and that he did not know where to go for help. He added that he was very lonely and had come all the way from the village by himself. He was unaccompanied, he suffered from a disabling condition and had been continuously sick for a year or more.

The team of Heartfile went beyond providing financial assistance for his treatment. They accompanied Mohammad to the doctor and requested that he be attended to and admitted to the hospital. The doctor graciously responded to the request and Mohammad was admitted that very day. At last, he had a place to get help from and a bed to lie on. He was approved for financial assistance and the surgical procedure was to take place within three days. Heartfile rekindled hope in this poor patient and energized him. He now carried hope through his own internal grit and determination.

He was treated but his poverty would persist and his lifestyle would continue to worsen on account of the loans he would have to pay back. We had to move on, but only after sharing the pain of Mohammad and taking some of it away.

Victims of Violence and Terrorism



The second category of victims includes those who have been Victims of Violence and Terrorism. Many men and women have to face violence caused by armed conflict, terrorism or unequal power relationships between men and women and it has become a terrible reality. The impact on the health of victims is disastrous. There is little prosecution and the perpetrators remain unpunished and enjoy complete immunity. The victims become the poorest and most vulnerable communities. Survival becomes difficult and they are destined to a life of isolation and restriction. The stories of survivors illustrate the various forms of violence and their effects on their lives.

ABDUL MANAN - KIDNAPPED

Abdul Manan was a thin and wasted patient, listlessly sleeping on a bed in the medical ward of Lady Reading Hospital in Peshawar. He had an emaciated look. He complained of night fevers, lethargy, bouts of violent coughing and loss of weight. He felt dizzy and his stomach hurt. He said that his body was gradually weakening. These health problems stemmed from his kidnapping by Taliban insurgents in the Bajaur Agency of the Federally Administered Tribal Areas (FATA).

Abdul spent six months incarcerated in the tribal wilderness of the mountains of northern Pakistan, waking each morning unsure if this would be the day he was to be executed. He had been a driver for an influential tribal head of the area, a job whose risks had already taken their toll on him and his family. He continued to share his experience of captivity - everything gradually became meaningless; proximity to death had given him a painful awareness of life. He was frequently deprived of food and beaten. These were the darkest and most haunting moments of his life.

When he was finally released, he reconnected with his family and his old parents, whose memory weighed so heavily on his mind during captivity. He returned to a normal existence. However, his health deteriorated; he could not go back to work and finally had to quit. He was encouraged by his family to seek treatment and afterwards he found that he had tuberculosis.

The late detection of tuberculosis meant that the disease had spread and reached an advanced state. Initially, he had lived in denial, secretly fearing that his tuberculosis was untreatable. The cough persisted; his despair intensified. As his immune system weakened, with months of hunger and abuse, he could not fight the infection. Additionally, he and his family had to deal with the fear of ostracism often associated with the disease. As Abdul said himself: 'fighting the tuberculosis stigma has become personal to me.'

If the human costs were high, so were the financial ones. The family incurred heavy loans not only for his treatment but also to support the family as there had been no income for

sixteen months. This resulted in massive stress on all their lives. In Abdul's case, tuberculosis was an illness not only caused by poverty and malnutrition but also by abuse.

Abdul was admitted to Lady Reading Hospital in Peshawar under the care of a compassionate surgeon and his team in a ward where Abdul was given their full attention. His case was referred to Heartfile to be assessed. It was found that this was a genuine case. He was to be fully assisted on account of the duress and disease he suffered during detention and poverty. He underwent the decortication procedure to remove the surface layer of his lungs that was now restricting normal functioning.

It might be a lengthy and costly treatment before he fully recovers and can get on with a normal life but there is now hope, though no guarantee, that he will be completely cured. His case depicts the trauma inflicted on a poor person and his family because of illness and disease. It is a vivid narrative, the survival of a kidnapping and the terrible consequences of it on his health, which plunged him deeper into a dark world of trauma, illness and debt.

ROSHAN BIBI – DOMESTIC VIOLENCE AND TERRORISM

Her name is Roshan Bibi. She had been thrown into a long tailspin of ill-health and hospitalization. At 31, she should have been in good health, enjoying her life but instead she had spent thirteen years fighting death.

She lay motionless on the hospital bed, dressed in a blue gown, her thin legs protected by long white socks which are used so that the blood does not clot when the patient is in bed for long. She had very little movement and was gradually losing even that. It seemed unlikely that she would regain much of her former strength.

Roshan Bibi was unaware of the ward and the good services and environment being provided. She had on dark glasses. She had completely lost her sight when the socket bones of both eyes were crushed in a bomb blast detonated by a suicide bomber when she was eighteen. Her left arm was badly maimed. She had survived multiple gruelling operations earlier. She was lucky not to have met death, though the intervening years could scarcely have been crueller if she had.

While herself slowly coming to terms with so much loss – of her sight, of her mobility and independence, her youth and beauty – Roshan returned home with her several deformities to be the object of everyone's curiosity. Her real ordeal began then, as she was physically and sexually of no use to her husband, a coal miner and could not attend to her three very young children. Nobody attended to her and she was treated as a pariah. Being a disabled woman, she was seen as a loss of productive potential and a drain on family resources. Her spouse immediately took a second wife. Roshan did not give up as she had no option but to compromise with a life of miseries and ill-treatment. The deeply-embedded cultural values and negative social attitudes towards her resulted in domestic violence, inflicted by her spouse and her mother-in-law. This she endured silently. It had an enormous impact on her physical and mental health.

Thirteen years later she was dumped at Lady Reading Hospital unable to breathe and eat. Having been exposed to radiation during the bomb blast, the genetic mutagens in her body reactivated after years of dormancy. She was evacuated from Shangla to Peshawar in a serious condition. She would have been left to die as she could not afford the treatment. Her case was referred to Heartfile and on account of the tragic story, the hardships she had endured at the hands of terrorists and her own family alike and the lack of any other support, her case was approved instantly. Otherwise she would have been left to die. She was lucky to have been referred to an eminent surgeon who performed an intervention for a total esophagectomy.

Her anxiety was overwhelming, lying waiting on the hospital bed that had been her home for many weeks. She missed her children. She stated that her home had become such a fearful place to go back to – a life of isolation and marginalization awaited her there. She added that she had been drained of all life and her nightmare was endless. Hers was a powerful and moving testimony of a most deserving but disabled, neglected and abandoned wife. Her husband even tried to capitalize on her miseries. He submitted false receipts for medical expenses which he had not incurred.

Roshan Bibi faced triple discrimination due to her disability, gender and poverty. Prejudice reigns within these categories. The twin discrimination of gender and disability will continue to be perpetuated unless there is an attitudinal change. Otherwise women will continue to be locked into terrible marginalization.

This case shows how a woman's life changes whenever she cannot cater to the desires of a man; how worthless she becomes with disability. The issue is how a woman's role is perceived traditionally and socially. Social and cultural constraints severely limit the lives of women with disabilities, sometimes as much as the disabilities themselves. The stigma around disability is so intense and pervasive that it made Roshan Bibi an invisible member of her family, her community and society at large. There is a critical need for the creation of an enabling psychological and physical space that supports the capabilities of women with disabilities.

This is the testimony of a woman who may never overcome rejection by her family and society. The fallout is unnerving: womanhood snuffed out as soon as it had begun; a marriage at such a young age which ended just as abruptly. Poverty and injustice were the core of Roshan's vulnerability and deprivation. Her own physical blindness was brutally compounded by her family's and her society's blindness to her need and distress. This is a story of human suffering, the result of a Taliban-led insurgency and the human cost of this conflict which will only be counted over decades.

FAIZA – A VICTIM OF VIOLENCE



Faiza was born to a poor family. She lay motionless and face down on a hospital bed, unattended, with both legs fractured. One leg was plastered; the other one, which sustained multiple serious fractures, was awaiting surgery. This surgery is possible only if the financial costs are met. She lacked the support of a nurse; her breakfast remained next to her hours after it was served. She was unable to eat it by herself as she needed someone to feed her. She spoke from the heart.

Faiza was a recent divorcée, aged twenty-eight with three minor dependents, the head of a single-parent household and a survivor of domestic violence. She had been on her way home after attending to her domestic work in two homes; she had just purchased some cheap vegetables for a meal for her children when, crossing a busy road, she was hit by a car.

Faiza's pain, confusion and helplessness were obvious. She stated that she was worn out. The shadows of an older grief were apparent in her face. She related the dark memories of physical, emotional and mental abuse at the hands of her drug-addicted spouse for twelve long years. She was still suffering the trauma of abuse and divorce when the accident occurred, further adding to her misery and duress. The strain of poverty and injury had visibly drained her.

Initially, she refused the needed care and treatment because of concerns about the cost of the treatment. She worked as a domestic help, complementing her earning by tailoring for ladies. She was a trained seamstress but said that she could not depend on this skill as her clients were not regular. She now feared that she would not be able to work for a long time and that her anguish and pain would be prolonged.

She said that this helplessness was her personal hell. On the other hand, she added that she would not give up because of her children and would continue to live for them. She was told that her weakened immune system was partly due to stress resulting from her long years of physical and psychological abuse. Self-neglect was also apparent in her case.

In this case, the issues of violence had had important consequences on Faiza's physical and mental health. She insisted that the violence she suffered during twelve years of marriage enhanced her resilience. On one hand, she had taken control of her life now and was living as a single mother on her own terms; on the other, she looked extremely depressed and anxious, chronically fatigued, isolated and withdrawn, quite apart from her seriously limiting, long term injuries.

The assistance of Heartfile exemplifies its effort to change attitudes towards poor patients and to come to their assistance at the direst moments of their lives. Heartfile plays a small part in reducing poverty by supporting women's efforts to uplift themselves and their children.

The dilemmas that confronted the treating clinician when this patient could not afford medical care raised profound issues of social justice. The costs of violence along with injury

were tremendous. With Heartfile's assistance, the costs of treating serious physical injury were covered. Heartfile raised the matter of her psychological problems and her anxiety with the hospital, which would arrange a psychiatric consultation. She was unable to tolerate, ignore or shrug off her problems when I met her. Perhaps she will never be fully restored.

BIBI RABIA – A VICTIM OF CONFLICT



Agony, mixed with inner torment, were apparent on Bibi Rabia's face. Silent pain and suffering, were how she endured illness and multiple deprivations. Rabia was a very sick woman, from an impoverished household, who had to bear so many burdens – financial troubles, horrendous deprivation, severe ill-health and worst of all being trapped in the vortex of poverty. Poverty and ill-health had combined to give a fatal blow to Rabia.

Rabia came from a small village of South Waziristan where terrorist insurgency, military counter-operations and a deplorable socio-economic situation reigned free, all of which contributed to the high prevalence of infectious diseases such as tuberculosis. She was only thirty-five, with a medical history of coughing, heavy sputum and fever for eleven months. She had been on Anti-Tuberculosis Treatment (ATT) for the preceding nine months.

Rabia was being treated at the local government hospital. Her health did not improve and she was referred to Lady Reading Hospital's Outpatient Department in Peshawar. Here she was put on ATT for another two months. The commute between her distant village and Peshawar was hard. With the difficult travel and her health deteriorating, one of her lungs

had been destroyed and she was referred to the thoracic department of LRH for immediate treatment. A pneumonectomy was part of the treatment plan.

A pneumonectomy is a surgical procedure to remove a destroyed lung. This procedure would remove half of her breathing capacity. The aim of the surgical intervention was to eradicate lung diseases, typically tuberculosis, as in Rabia's case. It was a serious procedure and was performed because the doctor suspected cancer. It was hoped that the operation would offer a better chance of survival for Rabia.

During her stay in the LRH thoracic ward, she was amazed at the care and commitment offered by the staff to her and to all the patients. She stated that with her disease, it was all about hope and living and that for her LRH was the only source of hope. She added that it was important to trust the system that LRH thoracic ward put in place because it had already worked for so many people. The team would do everything that was possible to treat each individual and to provide a quality of life to each individual patient.

The symptoms were dyspnea (shortness of breath), haemoptysis (coughing up blood), chronic coughing, chest pain, fatigue and loss of appetite. She had been ignoring the symptoms. She spoke eloquently of her experiences: "I have no knowledge of my ailment, or how it is going to affect me. My journey with the illness has been hard and it began almost five years ago. I have floated from hospital to hospital, both in my region as well as in Peshawar, for check-ups and treatment. Tiredness caused by the search for treatment has been extremely taxing. During the process I felt I was neglected and here I am told I have a destroyed lung. Who is to be blamed? I was not told about every stage of my treatment. Nobody held my hand, except my family to a certain extent. My family was at a loss; none of the treating doctors was by my side. Is it because I am poor? I am a woman? I know that I may not be promised a tomorrow but at least now I am in good hands at LRH."

From her comments it seemed that prior to her treatment at LRH, Rabia and her family did not have any understanding of her illness or of the drugs or procedures involved. This reflects the total lack of any general patient-doctor relationship for poor patients. The family was shocked and terrified when informed about her disease. She had to travel great

distances to find a competent surgeon who was an expert in the procedure of pneumonectomy. Unfortunately, surgery to remove the lung was the only option left.

Why had Bibi's health deteriorated to such a level in spite of her previous treatment? The causes might have included: an interruption of TB treatment caused by lack of drug supplies, a lack of monitoring and compliance with the treatment offered, inappropriate treatment given by the treating doctors, or missed doses, or failure to complete treatment. She could also have been drug resistant. So many questions remained unanswered. Another major negative factor was the illiteracy of the whole family and the patient herself.

Being poor and sick had been an almost fatal blow for Rabia. Her poor dietary and stressful lifestyle took its toll on her. She would continue even after the procedure to live in a state of poverty. The Taliban insurgency in Waziristan has led to widespread poverty, a struggling economy and the absence of health care facilities. Thus, Rabia was in difficulties on account of the long conflict, poverty and lack of health care. She was to return to a tent pitched on her home, destroyed by the Taliban, without the basic amenities and her spouse would go back to road construction on daily wages to support their family of ten.

Full recovery might take three months or more but hopefully the risk of post-operative complications would be avoided and her quality of life would then improve.

JANKHAIRA - WITH AN ABUSIVE AND MENTALLY-ILL SPOUSE

Jankhaira lived in a remote village of the tribal belt and was sold into marriage for head money or '*saar paisay*' at the tender age of fifteen. Until that time, she had never set foot outside the house. Little did she know that she had been married off to a mentally-ill man. She was repeatedly raped and molested by her deranged spouse. She struggled but was often beaten up, dragged through the house and finally raped. Marital rape refers to forced sexual contact between spouses. This was not recognized as a criminal act in many regions until the late twentieth century.

The criminalization of marital rape has required an overhaul of centuries or even millennia of common and existing law and plays an important part in the debate of the rights and responsibilities incurred through marriage. Centuries of law assert that marital rape cannot exist, since women have historically been treated as property rather than rights-bearing individuals in marriage: it made little sense to lawmakers to stop a man from sexually using his supposedly rightful property. According to the most common law systems throughout history, once a woman is married her body belongs to her husband and she has no right of refusal.

As a result of repeated rape, Jankharia, a mother of six at the age of only 28, had suffered deep emotional and physical wounds. Her married life was a living hell and the painful disease which she developed made the agonizing life she already led worse.

Jankhaira had been unwell for several years and had borne six children, the last one as recently as a month before Heartfile was approached. She had suffered silently throughout these pregnancies but she became really ill with her last baby and she was packed off to her brother, along with her children, after giving birth. This action was the decision of her in-laws, who felt she was too much of a burden as a sick mother, wife and daughter-in-law, who could neither contribute to the household nor attend to her deranged spouse.

Jankhaira was seen privately by a doctor who referred her to Lady Reading Hospital, where her X-ray and CT scan showed a mediastinal mass in the anterior (front) mediastinum. She had been complaining of severe chest pains and had suffered fever during this most recent pregnancy. A mediastinomy, which is the creation of a small opening in the upper chest into the mediastinum, was planned. The opening would allow the surgeon to examine the area between and in front of the lungs and chest and remove the mass. This procedure was supported by Heartfile, or else she would have been taken home without treatment.

At the age of 28, Jankharia lay on her hospital bed, attended by her nephew, with her one-month-old baby girl lying by her side. Her sad eyes reflected anxiety, stress and heartache. The birth of her baby girl - instead of a boy - was mourned as a source of guilt and despair by her family. She said that no one had informed her family that her prospective spouse was mentally ill.

Jankhaira's husband was already out of work. He was bi-polar, exacerbated by paranoid schizophrenia. Mental illness ran in the family. He had been repeatedly hospitalized in a locked ward and was on medication. However, the illness kept creeping back. He was often abusive, both verbally and physically, which Jankhaira had to endure silently. She had no control over her body and he was obsessed with sex. She added that every day she lived a nightmare and felt she was on the verge of losing her sanity. Her husband could not be left alone.

"During the time he was hospitalized," she said, "it was a relief to me, as I could breathe. I would worry for him and this worry would never end. It was heart-breaking to watch him deteriorate gradually. You have no idea what it is like living with a mentally-ill spouse. His mental illness had torn the family and my life apart. In my home there was no joy, no chance to relax for a second."

She felt her own health gradually deteriorating. She was mentally and physically exhausted all the time. She said that she had only bad days; the good days never came. She had no support from anyone, which is crucial in such a situation. She accepted life one day at a time and it was a gift for her children that she was alive to care for them. Poverty and deprivation added to her plight.

The religious and ethnic conflicts, the dehumanizing attitude towards her as a female, the extended family system and the role of her in-laws in her daily life were major additional stresses. She was marginalized in all spheres of life. Her mobility was restricted; she was confined to the home.

Jankhaira belonged to the tribal belt where women live in constant fear, where their movements are strictly controlled, where violence against women is pervasive within the private as well as the public sphere. Women fear being humiliated when they step out on the street even if they are covered from head to toe. They face many difficulties, including a lack of access to education and total lack of freedom of movement. The literacy rate for women there stands at barely 3%. Society in that region confines all women's actions; boundaries are placed on their behaviour and activities and only limited contact is permitted with any outsiders and even then, under the most severe constraints.

Jankharia had never enjoyed any power or rights. She had sacrificed her hopes. She never uttered a complaint or voiced her silent screams of pain and had spent her life, in her parents' home, as well as her husband's, in complete isolation. The mental illness of her spouse and her own ill-health, she mentioned, had given her nothing but heartache. She wished that she could walk away and get on with her life but she was too bound by traditions in a very conservative and traditional society and thus she was destined for a life of enduring misery and suffering.

RAJEDA – A VICTIM OF VIOLENCE

Rajeda was a twenty-year-old mother of an eighteen-month-old girl. She had been married off by her family to a stranger in a small village away from Thal near the Pakistan/Afghanistan border. She had been born and brought up on the outskirts of Peshawar.

Her relocation after marriage left her without family support. The marriage itself lasted six months and during this time she suffered much abuse from her husband. Rajeda said that she was constantly subjected to unbearable physical and mental violence. Six months pregnant, she was dumped back at her mother's home. After having been abused emotionally and physically, she had been abandoned for the past two-and-a-half years by her spouse. Abandonment by spouses constitutes an emerging form of violence against women, both in its intent and effect.

Back home, she and her child were considered by the family as a shameful burden. Interpersonal conflict within the family intensified her sense of rejection. After so much spousal violence, she then suffered at the hands of her parents and siblings. She said she had no option but to try to escape the awful circumstances of her life. She had been isolated in the midst of a poverty-stricken, overcrowded home and felt that she had no hope of breaking the cycle of suffering. Her attempted suicide was a cry for help. Nobody in the family understood. She had looked for family support as a bolster against her despair and found none.

Two months later, she was rushed to Lady Reading Hospital's Emergency Department in Peshawar after she had swallowed bleach/acid. She was administered treatment as an outpatient. She was again admitted to the Cardio-Thoracic Ward of LRH and diagnosed with oesophageal stricture, which is a gradual narrowing of the oesophagus caused by a corrosive intake. Rajeda was finding it difficult to swallow. The doctor said that the lining of her oesophagus had been damaged and scarring had developed. When the scarring occurred, the lining of the oesophagus became stiff.

In time, as this scarring continued to build, the oesophagus began to narrow and this resulted in swallowing difficulties. The cost for an esophagectomy was requested from Heartfile and quickly approved. The team of surgeons decided on the operation table to perform a procedure of dilation and an esophagoscopy in the hope that she would recover. A dilation is when the oesophagus is stretched by either passing a dilator or air-filled balloon through an endoscope. Repeated dilation may be necessary to prevent the stricture from returning. An esophagoscopy is a test designed to examine the oesophagus by using a thin lighted tube called an oesophagoscope. In case her condition did not improve the next step would be an esophagectomy which is a procedure to remove part of or the entire oesophagus. After it is removed, the oesophagus is rebuilt from part of the stomach or part of the large intestine.

Rajeda looked anaemic, malnourished, in extreme ill-health. The poor economic condition of the family was visible. Poverty-stricken and with the additional scars of physical and mental torture, Rajeda felt that life was not worth living. The suicide attempt could have led to the end result of death even if that was not her intention deep down. Death would have left the family and her baby bereft and suffering with many unanswered questions. She was fortunate to receive a second chance in life.

The family was faced with shame and guilt. They wished to deny and forget the incident as in this case it had been inferred that they were responsible for Rajeda's attempt at suicide. Her action reflected a rational choice to escape from her structural, cultural and gendered oppressions. Yet the root cause goes beyond "individual pathology"; it is the cultural control and marginalization which led Rajeda to such deep desperation.

These are frightening inequities which need to be addressed. Social consciousness should be created about the individual rights of women, but unfortunately, the vast majority of women remain life-long victims of class, region, language, religion and even dress, illiteracy and poverty.

The patriarchal forces in Rajeda's life had perhaps made her more vulnerable to suicide. Her physical sufferings hopefully ended with the surgical procedure, but it is not certain

whether her mental state improved drastically. Rajeda' s psychiatric disorder meant a vulnerability for her child as well, no doubt affecting her ability to parent her only daughter in the future. It was doubtful that the mindset and behavioural pattern of her family would ever change. Rajeda would continue to bear the wrath of the family for having brought shame to them by attempting suicide. In this case, family conflict and a violent husband all contributed to her psychological ill-health.

Rajeda' s case exemplifies a tsunami of spousal and domestic abuse, child protection issues, suicidal tendencies, poverty and deprivation. Her abandonment had taken on frightening proportions, jeopardizing her emotional, social and economic survival in a country where no safety net exists. Both the abandonment and the desperate act of drinking bleach/acid had permanent debilitating and far-reaching consequences for her, her child and even her family, who were unable to escape such cultural and social taboos.

TABINDA – MARITAL RAPE AND GUNSHOT VICTIM



Tabinda's story is a shocking tale of abuse, survival and a woman's unwavering will to live. She survived a gruesome attack. She was twenty-eight years old, married off at eighteen to a first cousin. He had been abusive throughout. She bore four children despite constant abuse and endured this with her husband for ten long years. She thought that he was going to change and that she could change him.

All these years she felt sad, depressed and alone. She lived in fear of her abusive spouse as their marriage crumbled and chillingly foretold her fate to her mother. He was verbally abusive and then the emotional abuse turned violent. She got beaten for every little argument. She added that she was fast falling apart. Her in-laws bore silent witness to the violence she endured and often instigated him to beat her up, fully supportive of their son's cruel violence. They had concealed his drug addiction prior to their marriage, trapping her into a relationship. She felt her only value for them was as a child-bearer. She stated that

the women of the house were the worst lot as they were utterly insensitive and lacked all fellow-feeling for another woman.

Life became frightening. She was constantly a victim of marital rape and the man became more abusive. She fled from him with her children to the refuge of her mother's home. She sought the protective guardianship of her mother against the violent and sadistic spouse. She wanted to take her life back and wanted to let everyone know that her spouse no longer had control over her. She expressed a will to live for the sake of her children. She stated that she had been robbed of her youth and her physique but not of her spirit. It was the children who kept her going.

She lived at her mother's house for ten months with her four children. The spouse would occasionally visit them and plead for her to return. She had in the meantime filed for 'khula' or divorce. After fleeing her home, she thought that she had escaped abuse. In fact, the most dangerous moment for women leaving abusive partners is the period after they leave. During one of his visits he attacked her. The abuse turned deadly when he went from ranting to holding a gun. He shot her in the legs at point blank range. Against the odds she survived.

She had been lying still on a hospital bed for eleven days when I met her. She said that she had survived to tell her story. Tabinda's mother had the heart-breaking task of sending the children to the abusive in-laws as there was nobody to take care of them, as she herself was Tabinda's attendant during her hospitalization. Tabinda had a brother who was home, but he was epileptic and incapable of caring for them. The children were always terrified. Now they had been witness to the horror of their mother being shot and perhaps being lost forever.

Tabinda's mother, a widow with a dependent disabled 30-year-old son, was very poor. She was a home-based worker who had set up a 'tandoor' at home and made *nan* (bread) for sale in the village. She and her son had also often been beaten up by Tabinda's drug-addicted spouse. She said she had always suspected that the man was "no good" but the shooting came as a horrible shock for all of Tabinda's family. The family was already being

shunned for having given refuge to Tabinda, an act which in conservative societies was considered taboo and tainted them by association.

With the perpetrator still at large, Tabinda bore the physical and mental pain of the injury and of the separation from her small children. This man, who should have been faced with attempted murder, weapons' offences and child endangerment charges, was free. Tabinda had suffered unnecessarily at this man's perverted whims. Who would see these crimes? Who would stand up for her? Would she be able to move past the trauma? Would her emotional and physical scars ever heal? Would her children's mental wellbeing be forever damaged?

Tabinda's case depicts a gory authenticity that would horrify anyone. It haunts anyone with a conscience. Is there any spark of hope for Tabinda? The disparity between man and wife goes unnoticed in a male-dominated society with women's inability to change circumstances. The harsh life for Tabinda would continue unquestioned and unchallenged.

Tabinda's story portrays a sense of loneliness, gripping and strong. She shared the worst disturbing events of her rapes in frightening detail. The dark side of reality had touched her to the core. Women will continue to be routinely subject to the most unimaginable horrors. It is a saga of sadness. Tabinda's story reflects strongly an underlying misogyny which regrettably forms the foundation of the local culture. Tabinda's plight is deeply disturbing. The world needs to wake up and understand the plight of women in more conservative societies.

She would have gone home untreated and maimed for life, had she not been noticed by Dr. Sania during one of her hospital visits. She was struck by the painful look in Tabinda's eyes. The outcome of Heartfile's assessment is reflected below. Tabinda's procedure was financially supported by Heartfile and additionally Tabinda was provided with some cash towards the purchase of milk and fruit.

Following her treatment, Heartfile provided Tabinda with crutches, funded the construction of a toilet and a water connection, basic but precious amenities from which she would always benefit. Her rehabilitation is now being monitored and hopefully she will

be able to lead an independent and as much as possible, a normal life; but the physical and emotional scars of violence will remain for a lifetime.

Tabinda revisited:

Mariam Mehdi visited Tabinda after ten months in her small village near Jhelum. She was shot on 20th March 2012, an incident that still haunts her dreams. We revisited her in her small village near Jhelum ten months after Heartfile helped her. She greeted us with the following words: *"I have awakened to a new life of constant pain, loss and brutal challenges. I am only 28 years old. I am terrified and heartbroken. I cannot describe my ordeal, the shock and the pain that life has stored for me."*

She shared with us that she was learning to live with disability. However, it has changed her forever. She added that she is at times paralyzed by the anxiety of having to survive on one leg. She has been given crutches and needs a prosthetic leg.

Tabinda is part of an 'invisible majority' – female victims of violence facing the long-term consequences of that violence – stigma, ill-health, poverty and marginalization. She seemed to leave it to fate and continue on a journey of resolve and acceptance. She faced the reality of life as a mother with disability and without her children. Her story speaks of the power of a woman's spirit to survive.

She could not help but portray the violent and terrifying incident and its after-effects. This reflects how she has been scarred and traumatized by the incident. The shooting and the loss of her leg was the most devastating event of her life.

She again narrated her ordeal and its deep shock, but with courage. She related the absence of her loved ones – her children – the void and the deep and unbearable pain she was constantly experiencing. She said that she was attempting to pick up the pieces but everything she had ever known had been ripped away from her. Tabinda was a broken

woman and had repeatedly thought of taking her own life to escape the nightmare. However, this feeling had subsided with time.

She said that she lived to fight another day but at times she had no strength to pick herself up. She realized that she was alone with none of her four small children; they were nowhere in sight and she feared their being abused by her cruel, violent in-laws.

She had to relocate, she said, after her return to the village, on account of continuing threats by her husband, the perpetrator of the shooting that changed her life. She lived with her mother and brother in two rooms, provided by an influential local in the village, after Tabinda's mother's plea to him. The shelter was without water or sanitation, and thus, the family was deprived of very basic amenities which are strong poverty indicators. Life was hard as she could not contribute to the housework as much as she wished. Until Heartfile built a bathroom for her, she had to depend on her brother to take her to distant fields—on a bicycle—in the early morning and late evening so that she could relieve herself.

She expressed her wish to improve her skills to be more independent. With part of the monthly stipend, which Heartfile provided, she was able to buy an earthen oven which is being installed on the premises. She found out from women in the village the possibility of baking bread for sale to the village households. She hoped that this investment would bring her an additional income as the stipend is only for a temporary period.

Tabinda's story is a sad, heart-breaking and tragic one but what is remarkable is that she shows a lot of perseverance that perhaps comes with tragedy. It is a most powerful and haunting testimony. It is a case that teaches one about the situation of a victim of violence but it shows also the true meaning of strength and resolve as she goes on with her life.

It is a tragic situation of violence against women and its impact on the life of a young woman, a mother and now disabled. It is also a testimony of loss and bereavement. We were left struck by the blankness and loss in her eyes. She will remain among those who are under-privileged by way of status, class, wealth and comfort. Her story is an insight into how violence and persecution can result in stigma and shame and the fear of further harm.

Despite greater gender awareness and more gender sensitive laws, violence against women perpetuates itself and this abuse is often supported by a silent and truly shameful, acceptance.

ALI HASSAN – AN EIGHT-YEAR-OLD DOMESTIC HELPER

Ali Hassan, an 8-year-old boy who had suffered a hit and run incident, was in fact a victim of parental neglect caused by family violence. He came from a dysfunctional family, was abandoned by his father and was placed by his mother, along with his older sister, with a family as domestic workers. Their wages were directly handed to their mother. He was physically abused by his employer for not performing as per his expectations. His tasks were to wash dishes and clean the car.

Gradually, the beatings became harder and more frequent. Ali felt he had to escape this unending physical abuse and he ran away from his employer. At the tender age of 8 he did not realize the consequences of his actions. Little did he know that this escape would not be a flight to freedom. He was hit by a car and was left by the roadside with a fractured leg until the police brought him to the hospital. From then on, he was under the jurisdiction of the police.

While Ali was hospitalized the police immediately initiated the usual procedure of searching for his parents by making announcements in the mosques and markets of the locality. Their efforts went without response and he remained in police care.

Heartfile was called upon to help fund Ali's surgery. Heartfile's moral responsibility also saw it as important to ensure a safe rehabilitation for this homeless minor. As per the law, the minor had to be handed over by the police to the Child Protection Bureau (CPB), a government institution.

The ordeal for Ali continued. The CPB was a place where children were not optimally cared for. The staff's incompetence was apparent; children of conflicting ages, experiences and backgrounds were inappropriately grouped together, including those involved in drugs. No

medical attention was provided to the children and they were left to linger with infectious diseases. It turned out to be the most 'child unfriendly' and unhealthy environment, imaginable.

However, according to the rules set by the government of Pakistan, abandoned and runaway children are to be referred to the CPB. The fate of Ali Hassan was left to them. He was at a tender age, a victim of physical abuse and child labour, a runaway child, injured and destined to be perhaps further neglected by the CPB. Ali lost the joy and security of childhood.

This case highlights the numerous burning issues of abandoned and runaway minor children, child labour, child abuse and lack of medical support. It highlights weaknesses of institutions such as the CPB and the lack of accountability of functionaries who continue to inflict suffering on hapless children.

The idea of setting up the CPB was a commendable initiative, accomplished after the signing and the ratification of the International ILO Convention against child labour reflecting the fact that Pakistan is bound by the convention's obligations. There would be a better future for Ali Hassan, however, if the CPB's functions were properly monitored by the government and if the provisions of the Convention were implemented in earnest.

Ending child abuse and child labour is not just in the interest of children such as Ali Hassan, it is also an urgent national imperative for all the children of Pakistan. The issues related to the management of an established institution for child protection should be addressed urgently. Failure to address these concerns will simply perpetuate abuse and exploitation and exacerbate social fissures in Pakistani society.

Heartfile could not have changed the course of Ali Hassan's future, but it made a small contribution by paying for his surgery and by a follow up visit when he was referred to the CPB.

HUKAM SHIR - FIREARM INJURY AND VICTIM OF VIOLENCE

Violence is a public health problem in Pakistan with the widespread possession of firearms. It affects the entire social fabric of the country. The problem has its roots in the prevalence of small arms that has intensified with the Afghan jihad. The long history of conflict in Afghanistan has made the firearms trade substantial. The cross-border flow of firearms has led to easy availability. Pakistan is a very 'gun-friendly' society; nine in ten owners are unlicensed. At the same time uncontrolled proliferation of firearms and its consequences have never been addressed by the proper governmental authorities.

Hukum Shir, forty-six-years-old, responded to a situation in a benign attempt to pacify two hostile groups. However, both parties unleashed a hail of bullets and Shir was shot in the abdomen. He collapsed and was rushed to the Emergency Department of Lady Reading Hospital, Peshawar. This gunshot patient arrived in a relatively stable condition. He was admitted to the hospital with traumatic injuries and was treated as a forensic patient. He was an innocent victim caught up in the middle of a dispute; his injuries were unintentionally inflicted. He underwent an intubation and was discharged. He was again admitted after a week for respiratory distress, chest pain and a high temperature: he had developed a clotted and entrapped lung. The injury had developed into an empyema and the CT scan showed an entrapped left lung with a foreign element: that is, a bullet.

Timely management, surgery and a diagnostic fluid culture helped to appropriately treat the once healthy individual who was now suffering a massive empyema: a lung filled with pus that obstructed his breathing. The empyema was treated with prolonged antibiotic therapy and with extensive drainage and decortications. Heartfile paid the bills. He was the only wage-earning family member of a household of ten, including his elderly mother. He said that the incident had been soul-shattering in many ways for him and his family. He was already trapped by poverty. Firearm injuries are extremely costly to treat, and this burden fell heavily on the victim and his family.

Hukam Shir added that “this is a financially and medically difficult time for me.” This gun violence, apart from the physical injury itself, was associated with serious psychological, economic and social consequences for the family. Hukam Shir’s income decreased, he took loans to cover income loss and treatment. He was thus further driven into poverty and debt. He even began to wonder whether the shooting had been accidental. He felt helpless, his loneliness was frightening. His body was suffering, his soul was in torment. He felt that he had been confronted with an inhumane fate. This internal psychological torture was as unbearable as his infected lung. He was nostalgic for the time when he had been healthy. His fear was that the injury might cause significant morbidity, long-term physical and psychological disability and that it would directly impact his family. He was also afraid that he might be left with crippling disabilities that would eventually remove him from the workforce and destroy his chances for future work.

The case is about the impact and horror of gun violence. The propagation of firearms and the lack of effective arms control legislation are the underlying causes of the increased violence in Pakistan. Men are always at higher risk of firearm related injuries than women, due to the nature of society. Firearm injuries are often related to behavioural factors. Living in poverty is a risk factor for firearm-related injuries and deaths. The cost of treatment for the injuries incurred by survivors of gun violence are almost always catastrophic for poor people and so are their social implications.

Patients Suffering from Mental-Illnesses



The third category of victims includes patients who Suffer from Mental-Illnesses. Mental-illnesses in Pakistan remain a silent crisis. Mental issues come last on the list of priorities for policy makers; thus, the country remains without any mental health policies, programs or action plans. There are numerous factors such as socio-economic, the status of women conditioned by traditions and culture and increasing poverty, which are major causes of growing psychological and social problems. The personal accounts which follow are true stories of real people who have confronted violence, prejudice and discrimination. They face challenges and problems that are real and common

but if treated, their recovery is possible. Misconceptions about mental health are caused by lack of awareness and understanding. These misconceptions should be corrected, and access to treatment provided.

ABDUL GHAFOOR - DEPRESSED AND ATTEMPTED SUICIDES

Abdul Ghafoor's case was that of depression and attempted suicide. Ghafoor's family indicated that he had been depressed for a prolonged period resulting in fatigue, decreased sleep and low self-esteem. He would often become tearful and had also recently developed a tendency of getting into fights.

The issue with Ghafoor was that he had been suffering from a major depressive disorder. He was 47 years old, married and had a family of ten dependents. He was frequently out of a job on account of his sickness and unable to support his family. Unemployment significantly increased his psychiatric disorder through an extreme anxiety disorder and acute depressive episodes.

Abdul Ghafoor had had a history of hospitalizations for the past seven years. When met he had been admitted to the psychiatric ward of Benazir Bhutto Hospital in Rawalpindi, for treatment and observation following a suicide attempt, self-destructive behaviour and self-imposed harmful conduct. He was on his fifth suicide attempt this time.

The bigger issue was that since his family was illiterate, they had little knowledge or awareness of Ghafoor's mental illness. Throughout Ghafoor's illness, his family had either been in denial or simply were not able to realize that Abdul Ghafoor had a treatable illness. They did not immediately seek treatment at the stage when the symptoms of his illness were surfacing. They only focused on the myths and misconceptions surrounding the illness. In their attempts to understand Ghafoor's situation, they even took him to a faith healer at a shrine, because they believed that he was simply possessed by an evil spirit.

However, over time, Ghafoor's mental health deteriorated and the impact became lethal. Ghafoor began looking for ropes to hang himself, as well as sharp knives to slit his veins. He even tried jumping off the roof of his house to take his own life. As Ghafoor's behaviour became more violent, his family could no longer turn a blind eye towards his condition. They explained his behaviour as an inability to rationalize his situation. They finally realised

that it was important to obtain medical help and that the patient had to be placed on a 'suicidal watch' to counter his reckless life-threatening behaviour.

Due to his mental condition, Ghafoor was unemployed for years and as a result his twelve-year-old first son had to be pulled out of school to earn an income to support the family. The child was deprived of his right to education but had no other option but to rescue the family from starving. In addition, Ghafoor's spouse worked for meagre salaries in people's houses and in the process both child and mother were exploited by their employers. The mother accepted it as her fate but the son was more sensitive.

Studies have shown that children whose fathers suffer from mental illnesses are more likely to grow up to develop anxiety and depression. The eldest son became depressed and his father's mental illness had a devastating impact on his well-being. His level of contact with his father was not a normal one. Abdul Ghafoor could not assume his parental responsibility and he could not provide any support to his children and spouse. The child stated that he had failed to understand the nature of his father's illness and the reason why the burden of earning had been passed on to him at such a tender age and why he had to bear the duress and strain of a mentally sick father. He sadly shared the fact that his father had spent little time with him and his siblings, had shown no affection and his communication with them had been poor. The father never provided assistance to his spouse either. The abject mental health problems had a significant impact on the whole family.

Many questions of Abdul Ghafoor's eldest son remained unanswered. The fear of inheriting the father's illness was felt. There is some speculation as to whether Abdul Ghafoor would have been able to recover and assume his role of parenting. He might have been able to parent with support. His children could represent a goal in his recovery but there were other factors involved, namely: poverty, lack of continuous appropriate treatment by competent clinicians, a lack of awareness of mental illness by the family and a complete absence of a coping mechanism, which acted as strong obstacles. In the case of Abdul Ghafoor, poverty had been a determinant and a consequence of his mental illness. The lack of treatment and facilities and health care were other determinants.

Persistent ignorance about mental illness and misconception of it by the family and even some health providers, as a personal weakness or failing that can be willed or wished away, led to painful stigmatization and avoidance of the diagnosis by the family and Abdul Ghafoor's illness increased. There is a vicious, self-reinforcing cycle of poverty associated with mental illness. In the case of Abdul Ghafoor, long-term illness, inability to provide for the family and health concerns had intensified his poverty.

Poverty had further increased the risk factors for his physical and mental health concerns. The risk factors were caused by stress, anxiety and constant worries about money. Poverty is linked to high rates of mental illness and certain kinds of mental illness are linked to a great likelihood of living in poverty.

Heartfile came in to provide assistance for Abdul Ghafoor's medication but sadly, he had been lost to follow-up treatment. We are deeply concerned since a foreseeable result could be an eventual success in a future suicide attempt. We hope he will receive appropriate help before that. For us at Heartfile the key lesson is that access to medication is not the only factor in treating these patients. Social factors play an important part and in many cases, these are beyond our control.

AMNA - GENDER DISCRIMINATION



Amna was a 19-year-old, unmarried patient in the psychiatric ward of Benazir Bhutto Hospital in Rawalpindi, suffering from mental health problems. She was one of a family of thirteen and had had issues related to dysfunctional behaviour for several years. Her deteriorating mental health led to hospitalization on account of her violent and aggressive behaviour. In my assessment, her disorder had clearly developed from the many abuses inflicted upon her directly by her family, in addition to other stresses resulting from societal patterns.

The family held closely to the strong traditions and customs of the tribal belt to which it belonged. The gender difference between males and females is deeply rooted in the mindset and socio-cultural values of this society. Preference for sons ran deep in Amna's family and

this was part of a powerful tradition. There was a strong preference towards males, to the extent that the boys were fed first. Whatever was left was the only food given to Amna. She very often went hungry as there was not always enough for all the children. She was unable to adjust to a life circumscribed by this gender discrimination and the preferential treatment given to her male siblings. The preference manifested itself in neglect of Amna and her resulting physical and emotional deprivation. This deliberate inequitable treatment towards her over years, led to the destruction of both her physical and mental health. In some rural areas of Sindh and Punjab, the overall prevalence of mental disorder found in women is 64.8 per 1000.

Amna's home became her prison and more misery was added to an already wretched life. She continued to suffer tremendous physical and psychological stress due to the violent behaviour of her male kin. She was totally defenceless against this bigotry. When she reacted to the unfair treatment, the physical battering by her mother and brother began and it escalated over a period of time. She was initially a tacit recipient of the violence as she was in a position of abject dependence on the male authorities in the family. Amna endured the beatings in silence and internalized the pain and anxiety. However, later her voice was heard through her aggressive and self-destructive behaviour and her attempts at suicide.

The battlefield was her very own home – a place of supposed safety and refuge, which turned out to be a place of fear and violence. As well as the scars from physical and emotional abuse, Amna suffered severe nutritional deficiencies. Customs and traditions were used to justify the violence. She was constantly forced to lead a rigidly austere life and was always socially isolated.

The treatment pursued in Amna's case was psychiatric medication and sedation. This seemed the most appropriate and the most affordable option in the opinion of the treating doctor. Any psychotherapy, psychoanalysis or professional counselling in public hospitals is a rare and expensive, long-term method of treatment. In reality, it is a treatment only for the elite and the rich in private clinics.

Heartfile provided Amna with assistance for her medication. Beyond this, Heartfile could only highlight the state of mental health patients and how understanding of them and their

care is so inadequate still. The physical scars of Amna's sufferings may or may not heal, but the emotional ones will be all the harder for her to endure. The preferential treatment for a male child will be perpetuated; control by men over women's lives will continue. It is to be noted that the discriminatory treatment towards Amna and the abuse she sustained, has scarred her for life. Furthermore, these consequences, even though they were caused directly by her family, have had a toll on the family itself and placed a heavy burden on them as well.

Amna will continue to live in a system where religious injunctions, tribal codes, feudal traditions and discriminatory laws prevail over equity and justice. She will continue to experience poverty, isolation and psychological disability. She is a victim of extreme poverty and the deep biases against women which have created a remorseless cycle of discrimination. She was also vulnerable to severe physical and emotional abuse which has scarred her life. This, sadly, is all based in a context of continued and appalling discrimination against women, which remains a devastating reality.

AYESHA - ATTEMPTED SUICIDE

Her parents are haunted by questions. Why this trauma? Did they contribute to it? Could they have stopped it? They have been touched deeply. They have grieved in private. Because of the stigma attached to suicide, the parents have been calling it an accident. Suicide remains a criminal offence in most Islamic countries. Ayesha was engaged to her cousin. Would he marry her now? Her future had been damaged on account of her act.

Ayesha hailed from North Waziristan, an extremely conservative area of Pakistan where women are carefully guarded and every household is headed by a male figure.

Did Ayesha want to die? She had a history of mental illness. Her parents said that she had given some non-verbal clues, though these were hard to detect. She was often irritable and withdrawn. They now felt that it was a cry for help. She had been depressed for a long time and may have considered suicide as an option. She found herself increasingly dissatisfied with her life and often expressed thoughts of wishing she was dead. Ayesha had also been at risk of psychological marginalization because of her loneliness and despair. The family environment, the quality of the relationships and certainly the economic resources were all important factors. The two earning members of the family were laborers on meagre wages.

She was rushed from her small village in North Waziristan in a critical condition to the hospital. She was then moved from the emergency ward to the Ear, Nose and Throat Department, then from ENT to the thoracic ward as her respiratory and digestive tracts were severely damaged. She fought for her life for 25 days. Corrosive injury to the oesophagus was caused by the ingestion of a strong acid. Following an argument with her mother, Ayesha had gone to the washroom and gulped down a whole bottle of acid which was meant for cleaning. Her parents believed it was Ayesha's mental disorder that provoked her to take this drastic step. According to the doctor, her injuries would result in a lifelong debilitating condition and would probably later develop into an oesophageal cancer.

Progressive dysphagia (inability to swallow) of solids was an obvious symptom. She was so traumatized that she could not talk; she also showed signs of chronic cough and asthma. An endoscopic dilation was used to ascertain the extent of the damage. She was scheduled for an oesophagostomy (an operation in which the food pipe is removed), a procedure her family could not afford. Financial assistance was requested from Heartfile and the surgery was to be performed once she was more stable. Ayesha was being monitored round the clock in the Intensive Care Unit, when we saw her last.

Studies have shown that in South Asia, serious suicide attempts are to be seen more in females than males. Most of the victims are less than 25 years old. This could be related to psychological disorders, emotional instability, poverty or abuse. Ayesha's parents did their best to cover up the causes of the attempt. They voiced their regret at not having Ayesha treated for her mental illness and thus the suicide attempt could have been avoided. They expressed their guilt at not addressing her emotional issues.

In this case it is obvious that mental health issues were little understood or supported, let alone treated. The isolation stemming from depression drove Ayesha to attempt suicide as a way to call out for help. Suicide in many situations can be avoided with proper education and treatment.

MOHAMMAD AFRAZ - SUFFERING FROM MENTAL ILLNESS

Society has been inculcated with the idea that men have to be tough; men have to be strong. Weakness is simply not considered masculine. This code governing men's behaviour is one of the prime barriers preventing men who suffer from mental illnesses from seeking help. Many men feel that it is 'weak and unmanly' to admit to feelings of despair. It is easier for men to acknowledge physical symptoms rather than emotional ones and so their mental health problems can go undiagnosed. Many men simply do not believe they are even susceptible to mental illness. Thus, the mental illness of Mohammad Afraz had remained concealed, repressed and unattended for years.

The consequences of masking his illness had been devastating for Afraz. He had been out in the world suffering, with symptoms taking the form of hostility, irritability, verbal violence and abusiveness. He developed an episodic mood disorder which involved unusually intense, sustained despondency and major depression. He was at times verbally violent with family members. His anxiety disorder had progressed to a state in which he was always extremely withdrawn. The signs had emerged in early adulthood and had gradually led to completely dysfunctional behaviour.

Mohammad Afraz was a 28-year-old man from a distant and isolated village in Azad Jammu and Kashmir (AJK). His pervasive mental illness was such that he could barely manage his needs. It was an extremely difficult situation. He had spent his entire life in abject poverty. Life had meant existing mostly within the four walls of a dark, dilapidated room, remaining secluded and accepting a sedentary lifestyle where he spent day and night without doing any effective work.

He had lived his life on the benevolence of his parents. He was unable to live independently. The parents had experienced difficulty in letting go of their disturbed, adult son with this serious disability and were themselves extremely impoverished. Thus, he was a victim of absolute poverty, which equated with destitution. He had further suffered from a learning disability which denotes a condition of delayed intellectual development. This

status used to be called 'mental retardation' and is now called intellectual disability, or in some countries 'intellectual handicap' or 'being intellectually challenged'.

It had been a tremendous hardship for his parents too, to support a non-productive family member's food, clothing and ever-increasing cost of pharmacotherapy. The family consisted of five other members who were themselves somewhat mentally dysfunctional but who were not being treated. The father, who was the only wage-earning family member, had passed away two years ago.

Mohammad Afraz had had two stints of long hospitalization. Little attention was paid to him during this institutionalization. He was only put on medication and no consideration was given to his frame of mind or his reactions – although a large part of his problem centered on feelings and emotions.

"The agony Mohammad Afraz is going through is unbearable," stated his mother. She added, "I have spent my whole life watching the devastation that mental illness has wreaked on my family, which is unable to access any appropriate health care." She had been overwhelmed by the mental illness in her family and by their poverty. Nevertheless, she provided her adult child with as much support and comfort as she could. This culture prevails in Pakistan – though gradually there is emerging a breakdown in extended families. She said she would support Mohammad till her death and hoped that his siblings would then take care of him.

Those suffering from mental illness have always been socially rejected. This family suffered from a complete lack of community support and thus were collectively discounted. They were, additionally, excluded from all networks of family, friends and community. Social exclusion is a broad concept: it includes not only deprivation but problems of communal relationships, including stigma, forced isolation and failures of societal protection.

The family itself formed part of a stigmatized group, deliberately isolated, excluded and identified with poverty. The mother mentioned that she had learned to adapt to the poverty. Mohammad was demeaned, degraded and held back by poverty. Due to the shame, due to hopelessness, due to fear of rejection, he most often tried to avoid interacting with

society. This had, in turn, created further and deeper barriers. Mohammad's genes and family history also played a role. Poverty and stress were additional factors. He was not able to benefit from any up-to-date treatment for mental illness; for him medication was the only treatment prescribed. An individual plan which included psychotherapy (speaking therapy), and other modalities besides medication, could have helped him understand his illness. He could have been assisted in comprehending what he could do to resolve his life problems which had contributed to his illness. Such an approach is not adopted in hospitals in Pakistan and state of the art treatment is only meant for the rich who can pay for it; never for the voiceless, poor patients.

To improve the quality of life of people with mental health illnesses, rehabilitation centres are needed. These can provide vocational training to give them hope, to work on creating motivation, to remove their apathy and lack of drive and to make them capable of obtaining and keeping employment.

Work and economic independence for those suffering from mental illness is paramount. Thus, vocational training could make Mohammad productive, for which he would need to actively participate in a rehabilitation process. Unfortunately, his mother, who accompanied him, was unaware of her adult child's potential. Learning skills could help Mohammad reduce his anxiety and enable him to earn a livelihood.

Today's model of psychiatric care recognizes the importance of families as part of the treatment plan. His mother was the only family support and she could hardly understand the root cause of her child's ailment. Awareness should be raised about men's mental illness, their vulnerability and the silence surrounding it. There is a long way to go before the depth of society's ignorance about men's mental health issues is widely understood.

Heartfile has been supporting Mohammad's treatment.

MOHAMMAD ASHRAF – A CASE OF ATTEMPTED SUICIDE

Ashraf was admitted to the hospital in an unconscious state and the diagnosis revealed a tracheoesophageal fistula, an abnormal connection (fistula) between the oesophagus and the trachea that was caused by corrosive intake, drinking acid. An endoscopy showed grade I-II injury to the stomach and duodenum and this caused progressive dysphasia, cough, vomiting and poor intake of liquids and solids.

The attempt at suicide had devastating effects on Ashraf's body. There was permanent physical damage to his internal organs. He was a fifty-nine-year-old man with a family of six dependents. His wife was a tuberculosis patient, he had a medically challenged ten-year-old child and his thirteen-year-old son had been sent to work since the age of ten. He was presently deeply in debt and was facing multiple devastating problems. When he finally could not cope, he drank a cupful of acid with suicidal intent. He was in deep despair, unable to pay back debts or to provide for his family.

He lay doubled up on the bed, crying out in pain and vomiting. The mental anguish had been extreme. He owed large amounts to various money lenders. Desperate to escape from his problems, he resorted to suicide. He thought he would no longer have the burdensome responsibility of debt and family and would leave the family problems to his next of kin. The attempt was made; his intent was to die but he was rescued and resuscitated. His wife and children were mute with shock, fighting back tears. The effects on them were devastating; they stated that they were experiencing a range of conflicting emotions, feeling everything from intense emotional pain and sadness to total helplessness.

Ashraf worked hard and had wished for a better life for his family but throughout his life he worked as a slave for a few rupees. He came from an economically disadvantaged region of Pakistan where deprivation was endemic. His long-term unemployment with occasional work contributed to his poverty. The economic disadvantage had implications for his children in terms of education and resources.

His dilemma was that he lost all his dignity as he became more and more dependent on relatives for financial help. He ended being without assets, homeless and was the lowest of

the low with spiralling debt and no income. He felt that his problems could have been solved but he had no opportunity whatsoever to recover. Losing contact with reality, he felt that the only choice he had was to end his life.

Unfortunately, the family was illiterate and ignorant of the fact that Ashraf could no longer cope with the distress of his failure as a father. The symptoms were unnoticed and he fell deeper into despair over the crisis. His attempt at suicide was a cry for help. The anguish and suffering were too much and he was unable to see that he had other options. He had felt terribly isolated and his anxiety increased the isolation.

Surgical procedures and hospital stays, even in public hospitals end up being expensive for the poor. Heartfile paid for the surgery and in addition also gave him a small grant to enable him to recover. Normally once the surgical procedure is performed, such a patient would need medical follow-up for at least seven months and up to four years. Ashraf would head back to the village and then would be unable to afford to commute to the hospital and he would be likely to have postoperative complications. Poverty would therefore affect his recovery and his family's wellbeing. The extra grant would hopefully cover some expenses.

Counselling and other appropriate sessions could be of tremendous assistance in easing the intense burden and unresolved feelings that the patient and family would still face. However, for a poor patient and family these options were non-existent. Socio-economic deprivation and unemployment were clearly found to be associated with Ashraf's attempt at suicide.

NOSHEEN - ISOLATED AND MENTALLY ILL



There is a vicious, self-reinforcing cycle of poverty associated with mental illness. Pre-existing mental illnesses intensify poverty. Poverty increases further the risk factors for both physical and mental health problems. There are other risk factors brought on by constant stress and worries about money.

Poverty is linked to greater rates of mental illness and certain kinds of mental illness seem to be linked to a greater likelihood of living in poverty. In the case of Nosheen, the cause of mental illness was not only poverty but gender discrimination, cultural tradition, violence, abuse and the parental authority embedded in that tradition.

Nosheen, a 28-year-old student, had been physically and mentally abused by her brothers for having had friendly relations with a class-fellow. She was compelled to abandon her graduate studies; her movements were restricted and she was imprisoned in one room without contact with anyone. In her clear, calm way she complained of beatings and verbal abuse.

The only reason for this maltreatment was that she had defied tradition by befriending a male. Thus, she raised the wrath of the fiercely traditional and domineering males of her family and suffered life in a home governed by restrictions and traditions. She was otherwise, according to the family, considered a 'dutiful' daughter. 'Dutiful' is a relative term.

As a result of the consistently violent treatment she became psychologically dysfunctional. Her health was not given any immediate attention. The family had little knowledge about mental health: perhaps they were in denial or were themselves suffering incapacitating conditions and so were unable to deal with Nosheen's mental illness.

In such a traditional society, myth and misconception still surround mental illness. The dishonour caused the family to be withdrawn: such a society is often unable to accept the reality of mental illness. The family had great difficulty in dealing with Nosheen's bizarre and unpredictable behaviour. She was often extremely depressed and withdrawn and had long episodes of anxiety. She attempted to commit suicide and constantly had to be under surveillance. It became bewildering, frightening and exhausting for the family. The ongoing pressure and dismay caused by her condition became an unbearable burden for all the family.

Nosheen herself spoke of a long history of mental illness that had been aggravated over the years. She was attended in hospital by a supportive mother. Her case was referred to Heartfile for support with psychotropic medication. She was a patient with a personality disorder and co-morbid depression. She had also at some stage become hepatitis B positive, for which she was not being treated. Furthermore, she had been suffering since eight years with symptoms of mania and severe mood swings. Her history of abuse was associated with interpersonal sensitivity, depression and anxiety. She revealed a sense of helplessness and fear. She added that she felt she had a mental condition that could not be treated; that previous treatment or drugs had done little to help her.

She was one of a family of nine. The father and a brother were chronic diabetic patients while the mother had suffered an attack of paralysis from which she later recovered. Two

brothers, who were the earning members of the family, were on meagre salaries yet controlled the family and exercised full authority.

These brothers, since they had the economic power, felt that they were in a position of authority over Nosheen and thus felt they had the right to use physical and mental torture that, according to them, would bring her back on the 'right track'. The family had no assets and was extremely poor. Male power and traditions prevailed.

Both Nosheen and her sister were bright students and scholarship holders, which allowed them to pursue graduate studies, while the brothers did not achieve much through their schooling. Nosheen described a constant feeling of being useless and unwanted and this was reinforced by her marginalization within the family by its male members. She faced violence when she challenged any male tradition. How could she have asserted her right against tradition and parental authority, one of the most powerful institutions in Pakistani society? She was blamed for having dishonoured her family. This is where culture, custom and tradition intersect so negatively with retribution. Her family forcefully regained control over her.

Mental health is as much a socio-economic problem as a psychological one. Nosheen became a burden, an outcast within the family; there was no money available for her medication. She was parked at the hospital. The physical abuse had a strong correlation with the development of her anti-social and frequently impulsive behaviour. She was 'forgotten', considered useless and the burden of her care was unloaded onto the shoulders of the staff at the hospital. She was not being managed through individual psychotherapy, which is a mainstay of successful treatment. Here, there is the need to question the attitude of hospital staff towards poor patients - their trustworthiness, competence and caring. In the absence of such attributes, how could a patient be encouraged to express, confide, respect, trust and share various emotions?

Mentally ill patients in Pakistan who are poor, do not receive appropriate treatment and support. Society needs to be sensitized to their plight and their support elicited through a larger budget. More research and better treatment facilities are essential. Mental illness strikes at several levels, from depression to schizophrenia. It attacks individuals of every

age, especially young people who are suffering from various forms of mental hardship and disorder.

The story of Nosheen illustrates the serious consequences of abuse and violence on mental health. The harmful practice of abuse by males within her family was so embedded that other members of the family were unable to protect the victim. She defied tradition and thus deserved punishment and had to face violence. All the power to abuse and control was in the hands of the males. This power should be annihilated and only a collective effort with an aggressive approach at all levels of society can succeed in achieving this. Heartfile could not change Nosheen's circumstances. We could only see to it that the medications she needed were provided and that she was not discriminated against on that account.

SALMA – THE STIGMA SURROUNDING MENTAL ILLNESS

The stigma that surrounds mental illness is particularly pervasive in Pakistan. People view mental illness as something for which an individual is personally responsible. Treatment is complicated, expensive and hard to measure. Poor patients in Pakistan are treated with common medications and seldom with sessions of psychotherapy or beneficial counselling.

Unless attitudes to mental illness are changed, nothing will change. More attention is needed to address mental health and better treatments have to be devised. Doctors in Pakistan are, unfortunately, poorly trained to recognize mental illness. What makes it worse is that they have few tools at their disposal.

Salma was a thirty-two-year-old unmarried woman, the third of five siblings. Her entire family had mental health issues. Salma went from being a functioning individual with difficulties, to a seriously troubled, dysfunctional human being. Her daily routine rendered her at risk for more stress than the other members of her family.

She had many roles to fulfil as a daughter to a chronically depressed mother, a sister to two abandoned married sisters with chronic mental conditions, to a bi-polar brother and finally to a less mentally-disturbed eldest brother who supported the family from his meagre daily wages as a security guard.

Salma had shown the first signs of mental illness three years before. She remained a troubled and restless young woman. Her illness was episodic in nature; the precipitating factor was the psychosocial stress at home. It was so much to cope with that she physically collapsed. The disease had crept up on her slowly. She kept on drifting gradually downward and yet, to complement the family income, she continued to work as a maid.

Her inability to care for her family and their inability to care for her or themselves, led her to being an outcast with multiple admissions at the Institute of Psychiatry in Rawalpindi. She had to be hospitalized five times. She said that she had got used to the

illness and the hospital stays. She voiced the grievances she had as a carer to mentally ill siblings and her mother and as an employee in people's homes. Her low mood, her extreme disinterest, her feeling of helplessness and her withdrawal from the family and the whole world, kept intensifying. Slowly the shame and isolation were also reinforced within the family and community.

Salma said she had to come to terms with her illness, although it had ruined her. She stated that it had changed her forever and that she had been paralyzed by the anxiety caused by her ailment. It had been life-shattering and soul-destroying for Salma. She added that she was ashamed of her illness. The family did not talk about it as they felt there was so much dishonour attached. The stigma of having a mental health problem is a heavy one in Pakistan. Salma said that she did not have the strength to confront the stigma, to deal effectively with the dishonour and to be herself.

She added that mental illness can happen to anyone and should not be demonized. It has been an ongoing struggle for the whole family. She has been pushed to the margins by the family's apathy and society's attitude towards mentally-ill patients. Social and family factors had clearly pushed her to the edge and she added that she found her world chaotic. She had been put through the utmost misery and felt abandoned. She looked despondent.

The hospital where she had been a habitual resident, was her only saviour despite all the drawbacks. She was provided with psychiatric care through drugs now. She had been taking maintenance drugs for years, whose cost Heartfile would support now for her regular supply of medicines. Her mental state had deteriorated noticeably over the years. Further, for her, the psychotropic medications had terrible side effects to the point that it became hard for her to keep taking them. When she discontinued treatment, her condition became chronic. She then felt that the environment at the hospital was not conducive.

Her case was set against the backdrop of a dysfunctional family's mental health, her own illness and poverty. She was disadvantaged at several levels – being ill, being a woman and foremost being poor. It was clear that her mental disorder was also linked with poverty, powerlessness and alienation. Hers was a sentence to destitution and perhaps a sentence to death.

More women than men, the world over, are said to suffer from mental disorders. Mental ill-health and its profound stigma carry with it a tragic and tremendous burden of human suffering. The situation is worse when the affected person is a woman. Women's mental health needs to be considered in the context of social, political and economic realities.

The critical gap in availability and accessibility of mental services in Pakistan needs to be addressed. Salma faced critical issues such as shame, marginalization, isolation, despair and uncertainty, as well as the lack of mental health facilities in Pakistan.

Another notable aspect in this case is that mental illness and poverty interact in a negative cycle since the rest of the family members also suffer from mental illness. Lack of caregiving duties prevented the patient from healing, as the family was unable to provide her with any family support. In addition, the emotional responsibility that had fallen on Salma's shoulders and the combination of all the mental health difficulties of the entire family greatly increased the risk of continued or even worsened poverty.

SANA SIRAJ - ATTEMPTED SUICIDE

A suicide attempt is a sign of extreme emotional distress in that person's circumstances. Suicide attempts are much more frequent among girls as compared to boys by a four-to-one margin. Suicide in Pakistan has long been a social issue and is a common cause of unnatural death.

Reporting is difficult on account of the social stigma and legal issues that bind the problem. Given that suicide is prohibited in Islam, this issue is not openly discussed. It is considered a criminal offence, with punitive laws in place for those who survive the attempt. It was to escape from poverty and family discord that Sana turned towards suicide.

Sana endured great pain at the loss of both her parents; nobody understood her grief. Her parents were her foundation and they were suddenly ripped from her. She shared the following: "I have not been able to deal with the intense emotions, thoughts and stigma after my attempt at suicide. I am going through intense feelings of anger, guilt and shame."

She came from an economically disadvantaged area of rural Pakistan. Her deliberate attempt at self-harm occurred in the context of a family dispute and conflict with those close to her. After the death of her parents she lived with her only brother. She had constant quarrels with her sister-in-law and was cold-shouldered by her brother. Grief and social isolation contributed to her act of swallowing a strong acid – a household cleaning liquid. The constant harassment was a relevant factor. Her impulsive act might have been a cry for help.

She claimed that she was utterly frustrated by the harsh and unsupportive attitude of her brother. The ongoing conflict at home left her helpless; hopelessness pushed her over the edge. She was driven by feelings of anger, humiliation and desire to strike back against unjust and wrongful treatment. Her act, however, did not end in death as she had wished.

The family tried to conceal the act and claimed that the injuries occurred accidentally. She was rushed to the local hospital and had several dilatations for oesophageal stricture. She was referred to the Pakistan Institute of Medical Sciences in Islamabad for further treatment.

The narrowing of the oesophagus caused swallowing difficulties, pain and weight loss in spite of the treatment. The injury caused severe inflammation and damage to the oesophagus. The healing of the damaged areas caused the formation of scar tissues. A request for financial assistance was forwarded to Heartfile for a TTS (Through the Scope) balloon procedure which would be used to dilate the stricture. Dilation helped her breathing initially but the stricture recurred. The request was approved.

In this whole post-attempt process Sana was abandoned by her brother as a liability and a source of shame for him. She was given nothing by him but disdain. She added: "My soul is scarred by my brother's behaviour."

Her elder sister, who was also without resources, nevertheless took charge of Sana. She shared that she had incurred a debt of Rs. 100,000 for her treatment in three different cities and had had to relocate in search of treatment, determined not to abandon her younger sibling. She was protective of her orphaned sister who had endured psychological suffering at the hands of her only male kin, who should have been responsible for her care. Sana's eviction caused her sister much concern and she immediately gave her refuge in spite of having a large family that depended on the small income of her spouse, a manual labourer.

Sana was a Muslim. A strong religious faith is thought to protect against suicide. There are many facets to Islam that reduce the risk of suicide - including its being forbidden in the Holy Qur'an. Sana, despite strong religious belief could not cope with the situation. Following her attempt, Sana should have been assessed by a health professional (unfortunately, such a facility is not available in hospitals in Pakistan), with further medical and social support once she was back in her family and community.

Sana has had medical treatment, but the psychological problem needs to be addressed so that she does not try and harm herself again.

Refugees or Internally Displaced Persons



Accounts of patients who were either Refugees or Internally Displaced Persons (IDPs) constitute the fourth category of victims. Both refugees and IDPs are among the most vulnerable victims of conflict or disaster; they have been uprooted and live in a state of flight from conflict and persecution. Millions in Pakistan have been displaced internally by natural disaster and insurgencies and have had to flee their homes but have stayed within the state of origin. Both refugees and IDPs are destitute for the same reasons but IDPs do not enjoy the same legal protection as refugees. Their stories show their plight and dilemmas during ill-health, the impact on families and the hardships they endure.

BABA - WITH A GOITER

Baba, 63, was starving for air. He had a constant feeling of pressure in his throat, which was due to the compression of the airway and the large veins in his neck. The doctor spoke in grim terms – without an operation he would die a slow death; with the operation he may survive but there was also a high risk of death during the surgery. Such statements of uncertainty further demoralized him. Baba could not make the decision on his own; the consent of his family had to be sought for the surgery.

He was diagnosed with a retrosternal goiter which was suspected to be cancerous. A retrosternal goiter occurs when the thyroid enlarges downwards into the chest. The great majority of retrosternal goiters are extensions from the neck, but purely intra-thoracic goiters do occur. Retrosternal goiters are more likely to be left-sided. They are a common cause of compression of adjacent organs and may also harbour cancers. The management of this condition is surgical.

In the case of Baba, a total thyroidectomy was planned. Any suspicion of malignancy is always an absolute indication of the need for surgery. The thyroidectomy is an operation that involves the surgical removal of all or part of the thyroid gland. This procedure has several potential complications including temporary or permanent change in voice, temporary or permanently low calcium, the need for lifelong thyroid hormone replacement, bleeding, infection and the remote possibility of airway obstruction due to vocal chord paralysis. Baba had complained of progressively enlarged neck swelling for the past ten years and he also had a history of dyspnoea and change in his voice.

We had a moral and ethical dilemma to ponder. Baba's children had walked in and out of his life and had hardly left footprints on his heart. He had lost faith in his children and felt he had lost everything. He was now perceived by his children as a burden. Old age has never been a problem for South Asia where a value-based, joint family system used to prevail. South Asian culture has always been respectful and supportive of its elders. However, the culture is gradually changing as nuclear families become the norm against the backdrop of rapid economic development that is fast breaking traditions.

This patient had been forced to spend his old age alone. After he lost his spouse he was exposed to emotional neglect and a total lack of physical and financial support, having been abandoned by his family. He was too frail to fight any more battles. He lay alone on the hospital bed of Lady Reading Hospital with the covers drawn up over his head. When addressed he stared at us with a blank look, perhaps rolling over in his mind fragments of the doctors' words. He seemed to be trying to shut his eyes to the questions that were trying to force their way into his thoughts. Powerless to hold them back any longer, he uttered "Why me?" Tears welled in his eyes and fell down his face, but they did not provide any comfort.

Although he had a very wrinkled face, Baba was not as old as he looked. He was only 63, but illness and 28 years of service as a policeman had eroded his physical and mental health. He was already someone slipping away due to a chronic and progressive condition. He showed limitations in his ability to move.

He was originally from a little village in the Buner region where there is a strong Taliban insurgency. With the military operations in 2009 there were a huge number of internally displaced persons; Baba became one of these. Thus, he carried the trauma of being an internally displaced person (an IDP in policy jargon) who was more likely to be poor and sick, besides being an abandoned elderly father. Thus, he was doubly vulnerable.

Baba lived by himself in Peshawar and continued to work as a 24-hour watchman in a school. He stated that his body seemed to have stopped working physically and emotionally due to exhaustion. He had a limited income, no savings, no means of obtaining any more loans and was indeed very, very poor. His problems were compounded by the medical costs of his illness. He was bearing the brunt of digging deeper into his pocket to meet the treatment fees. He was already under great duress from a Rs. 300,000 loan.

In addition to having a serious ailment, Baba was demoralised because of this isolation; destitute and frail he was unable to fight any battle. Yet, he was forced to continue trying to cope with the additional trauma induced by displacement, abandonment and sickness. When he was told Heartfile would bear the cost of his surgery, he just could not believe it. Tears welled up in his eyes.

ABDUL QADEER - REFUGEE KILN WORKER



Abdul Qadeer had been complaining of coughing, breathing difficulties and an increasingly debilitating fatigue. He had also been having frequent asthma attacks. He was diagnosed with haemoptysis and an enlarging mass in his right upper lung lobe. His case was referred by Lady Reading Hospital to Heartfile for assistance with the cost for an open lung biopsy to ascertain the nature of the tumour.

An open lung biopsy involves surgery to remove a small piece of tissue from the lung. The sample is then examined for cancer, infection or lung disease. Heartfile supported the cost of the surgery.

Abdul Qadeer is an Afghan refugee, a Proof of Registration card holder, who was displaced with his family after intense bombing during the Afghan war in the 70s. He had spent fifty years working in a brick kiln. 'I was child labour when I started work,' he says, 'My family owed Rs.10,000 then. Today we owe Rs. 500,000.' He and his family are trapped in brick making and an endless cycle of poverty that has kept him indebted to his employers for years. He further added that he was paid hardly anything for his gruelling labour, barely enough to survive and certainly too little to pay off debts that have grown with each passing year.

He added that there seemed to be no escape for him or for his children and grandchildren, who were bound by their parents' contracts. He stated that his children had been held as collateral while he was in the hospital for treatment. He was haunted by guilt, despairing that his children would inherit his debts.

He said: "The work at the brickfields was arduous, gruelling and labour intensive and has greatly affected my family's and my health. I had no choice but to bring the women and children of my family to the brickfield for labour to improve the insufficient income. The conditions were harsh. We worked under hazardous conditions; we had to endure heavy manual labour. This included mud pugging by foot, brick moulding by hand and transporting loads of bricks on top of the head, which caused severe muscular and skeletal stress. A day's work was twelve hours and we worked for ten months without leave. We were off work during the rainy season but we were not paid during that period. The work load was great and the summer heat and that of the kiln, caused a very unhealthy environment. I was not surprised when I fell so ill." The high level of pollution at the brick kiln sites is a severe health hazard for the workers.

Abdul belongs to the most impoverished category of the poverty-stricken. He endured great loss after his dislocation from Afghanistan and was traumatized as a child by witnessing war crimes and forced displacement. He suffered the existence of a refugee for fifty years. While he came to terms with his loss and tried to move on with his life, he toiled away for five long decades in a brick kiln in the Karachi Port Trust. Abdul Qadeer's story is but one example

of the millions of bonded laborers across Asia who suffer the impact of traditional brick-making on their health.

Research has shown that sarcomas (a type of cancer) are caused by radiation and certain chemicals. Abdul was exposed both to radiation during the bombing in Afghanistan and to the combustion of fuel in traditional brick-making, for decades. The brick kilns emit toxic fumes containing suspended, particulate matter, rich in carbon particles and with high concentrations of carbon monoxide and oxides of sulphur (Sox) that are harmful for the eyes, lungs and throat. The inhalation over fifty years of a huge quantity of toxic elements from the kiln had been terribly harmful to Abdul Qadeer's lungs. Destitute and isolated, without any attendant, he lay on a hospital bed lost and emaciated.

He repeatedly said that he had been in bondage for most of his life. His family consisted of nineteen individuals. His four sons, of whom three were minors, aged ten to fourteen, also worked at the brick kiln. He feared that his grandchildren would also be forced to work for the owner as there was no way to repay the mounting debts. He feared that they would only be free when they died. He had no idea of what his debts amounted to at this time.

He continued to take loans from the same brick owner for basic subsistence, medicines and repairs of his hut, for his daughters getting married and for other reasons. Thus, the family had been kept captive, on site, in sub-human conditions. Males and females of the family spend hours in the slush, exposed to the cold nights, searing kiln heat, all the while inhaling toxic fumes. Thus, sickness is bound to follow.

Pakistan is a signatory to several International Labour Organisation Conventions, namely, the ILO Convention on the Worst Forms of Child Labour (No.182), ILO Minimum Age Convention (No.138), and the ILO Forced Labour Convention (No.29). They are all binding agreements, but not much attention has been paid, unfortunately, towards the implementation of these agreements.

Thus, cases such as that of Abdul Qadeer will recur, the rights of children will continue to be violated and forced labour will be inflicted on refugees as they are the least protected and the most vulnerable group in Pakistan. Health hazards and exploitation by brick kiln

owners will remain unnoticed, ignored and unaddressed. Abdul Qadeer's family and others like them, will never break out of the trap of bonded labour despite their hard work. They have become virtual prisoners of the owner and will continue to suffer physical, economic and social exploitation. The clutches of his debtors are so cruel that his family will most likely never be able to get themselves out of debt, for generations. There is an URGENT need to find a solution to move out of this utterly disgraceful and vicious circle.

GUL JAN - REFUGEE PATIENT WITH OESOPHAGEAL CANCER

By the time Gul Jan, a 50-year-old refugee from Afghanistan, arrived at the Pakistan Institute of Medical Sciences (PIMS) in Islamabad, he had already spent everything he had on a lengthy but ineffectual parade of local doctors. Gul Jan wore rags and had a vacant expression on his face. He appeared pale, as if any inner glow had been turned off. He was weak, emaciated and spoke with difficulty. His yellow, listless body lay on the hospital bed, barely able to move.

He had been diagnosed with cancer of the oesophagus and been operated on in Peshawar. Being unaware of any required post-operative treatment and not being financially able to sustain the stay in Peshawar, he immediately returned to Islamabad, where he lived in a refugee settlement. He mentioned that he was informed of the importance of rehabilitation therapy and of the long-term periodical examinations and life care needed but, he said it was not possible to adhere to the advice as he was too poor, and the cost of relocation and any further treatment was beyond his capability.

This neglect resulted in the return and spread of the cancer and he was soon back in hospital. The surgical procedure had been unsuccessful in removing all the cancerous tissue and the cancer had spread. His case of squamous cell carcinoma of the upper third of the oesophagus had been treated through an esophagectomy. It is to be noted that an esophagectomy is a major surgery. He had had neither chemo- nor radiation therapy as a follow-up to the operation. At this stage an esophagoscopy could not be negotiated due to the malignant structure of the oesophagus.

An esophagoscopy is a procedure done to examine the oesophagus by using a thin, lighted tube called an oesophagoscope. There was now no space inside Gul Jan's oesophagus for the instrument to pass. Two dilations were performed and a third one was attempted but failed. The doctors requested financial support from Heartfile to carry out a procedure through which the food pipe could be opened so that he could eat. This type of dilation of

the oesophagus is “palliative” so that even though the cancer cannot be entirely removed, the food pipe is stretched so that the person may not starve to death. Through Heartfile’s assistance the procedure was performed for which Gul Jan was very thankful. Every effort was aimed towards extending his life despite the pain, suffering and mental anguish involved, both because of Gul Jan’s disease and because of the repetition of this unpleasant and invasive procedure.

Studies have shown that cancer of the oesophagus is the third most common type of cancer among men in South Asia and the fourth among women. Among the risk factors for cancer of the oesophagus is a diet high in barbecued meat and very hot liquids. According to a major report from the US National Cancer Institute, red meat and processed meat eaters are 25% more likely to be diagnosed with bowel cancer and 20% more likely to be diagnosed with lung cancer. Red meat intake is also associated with an elevated risk of cancer of the oesophagus and liver. Barbecued meat is contaminated with cancer-causing deposits from smoke.

Afghan and Pakistani cultures include red meat in their diet. In fact, Afghani diet is greatly based on meat intake. Gul Jan, in spite of having been a refugee in Pakistan for much of his life, had maintained these dietary traditions. For all these years his identity as a refugee never changed. He did not learn the local language or integrate in any other way. He remained part of a marginalized and stateless class, without protection, the poorest of the poor. He lived in a mud hut in a slum settlement for refugees on the outskirts of Islamabad. His family of eleven was crowded in a small room without electricity, toilet or kitchen and they existed in such poverty, without water or sanitation, for years. He had worked harder than his body could bear. The indicators of his poverty were blatant. He could not even afford to send his children to school. Instead his young children were sent out to work as garbage pickers so that they could complement the income of the household. Child labour is banned, but the only option the poor patient had was to send his children out to work so that the family could survive.

Gul Jan said that he was not aware of the nature of the disease, nor of its seriousness. He was told by the treating doctors that he had cancer but remained in the dark as to the prognosis. He felt that the doctors had little time for poor patients. He was advised about

the necessary post-operative care after his surgery in Peshawar but was unable to follow up with this because of his scant resources. He seemed to have resigned from any further struggles and to have accepted his fate.

The disease, poverty, unemployment and effort to support a large family forced him to borrow money and he was now burdened by an accumulated and crushing debt of Rs. 200,000. He was penniless and disillusioned. He was terrified of what would happen to his children if he died. In the midst of his catastrophic and terminal illness, the welfare of those he would leave behind was always Gul Jan's biggest worry.

His was a case of a residual/recurrent cancer and it looked as if chances of survival were minimal. Heartfile faced an ethical issue when financial support was requested. It was felt that there was no choice but to support the patient, assisting his endurance of acute pain and attempting to delay the slow death. This also reflects another dimension of the physical and emotional turmoil of Gul Jan, his fear and his deprivation. Death was a real possibility for him.

HAZRAT BILLAL - A REFUGEE

Seven-year-old Hazrat Billal was whisked away from District Headquarters Hospital in Mardan to Lady Reading Hospital in Peshawar and was finally referred to the Pakistan Institute of Medical Sciences in Islamabad. He was fighting for his life. Born to parents who fled Afghanistan during the Soviet invasion more than 30 years ago, he had grown up in a refugee camp in Swabi.

He was diagnosed with aplastic anaemia, a blood disorder in which the body's bone marrow is unable to produce new red blood cells. Aplastic anaemia can also involve what is identified as bone marrow failure, in which case the bone marrow's red stem cells are also damaged. This condition can be acquired or inherited; in inherited cases the parents pass the gene for the condition to the child. In many cases of aplastic anaemia, the cause is never known. Aplastic anaemia is a rare but very serious disorder. It can develop suddenly or slowly. In Billal's case, it was sudden. The disorder tends to get worse over time unless it is diagnosed, the type is identified and it is properly treated. Treatments for aplastic anaemia include blood transfusion, blood and marrow stem cell transplants and medication.

Billal complained of shortness of breath, dizziness, headaches and chest pain. He often had flu-like illnesses that lingered; he had fever and skin rashes. None of these were taken seriously at first. His fever would not subside for very long periods of time. Once the seriousness of his illness was recognized, he was still unable to access the specialized treatment that he needed.

Life was already a struggle for Billal's family: his father took odd jobs as a day labourer and garbage-picker, risking his life collecting piles of refuse from disease-ridden ditches and wells. Billal started rag-picking at a very young age. He could not say how many years he had been doing this dirty, dangerous work; he had always done it, he said. His father had showed him the ropes so that Billal could help with the support of his family. This filthy work is symbolic of the deprivation of a family which has long endured poverty. Billal's father could not afford his child's treatment. Since the seriousness of Billal's illness had been

recognized, his father had not been working; thus, there had been no income. Being a refugee, the child could not access the Zakat and Bait-ul-Mal funds. However, through Heartfile's support, his treatment could commence.

The family was already living under difficult conditions in a tented refugee village without electricity, water or sanitation. The mother and children had to walk a long distance daily, carrying buckets of water back to the tent. They had been forced to relocate more than once because of flooding. The family was struggling to cope with the hardship of meeting the basic needs of food and water. They were being pressurized by local authorities, part of a common pattern of discrimination against non-citizens. Additionally, they were displaced, without any family or community support. The father was without refugee or asylum papers: this is the group which receives the worst treatment. The family found themselves among those who were forced to live in deplorable conditions, constantly deprived of proper nutrition and with no education available for the children.

The referral of Billal's case to Heartfile by the treating doctor at PIMS opened a door that would otherwise have remained closed. Heartfile pledged to cover the cost of the complete diagnostic package for bone marrow tests. Prior to a bone marrow transplant (BMT), a battery of tests is carried out to ensure that the patient is physically capable of undergoing the transplant. These tests also help the BMT team identify potential problems before a transplant and to avoid potential complications afterwards. As Billal's case was critical, it became a high priority for Heartfile.

Billal's case depicts the plight of refugees and their displacement. This was a family that was facing severe hardship with the combination of extremely poor living conditions, total poverty and the lack of access to health care. The father talked of physical and emotional hardships such as isolation, discrimination and exploitation. Their exile in Pakistan had been traumatic and disorienting. He felt powerless and realized that he was unable to rebuild his life afresh. His already fragile life had been shattered with the illness of his child.

The family was suffering the deepest form of poverty – the total lack of social as well as economic resources: not knowing where to access medical treatment, how to afford it and how to cope with the burden of their debts. The father said that their past had gone and the

future was in jeopardy; they lived in the present from day to day, hand to mouth, totally dependent on others for survival and for the treatment of his child. Even those 'others' were difficult to find for the most part.

The neglect of refugee issues has led to increased social vulnerability of this community in terms of lack of access to health care, among their many other deprivations. All this has further intensified their greater physical vulnerability with lives full of misery.

INZAR GUL - OESOPHAGEAL CANCER

Inzar Gul, a 55-year-old woman, reported to her local rural hospital with complaints of dysphasia for solid foods which had lasted for more than one year and had progressively increased in severity. She had also developed difficulty with swallowing liquids. She hailed from a distant village in the Khyber Agency, had sought local treatment at Bara and was referred to the Hayatabad Medical complex in Peshawar where the endoscopy revealed oesophageal cancer. She was immediately referred to Lady Reading Hospital for specialized treatment.

South Asia has very high rates of this type of cancer. Men are more than three times likely as women to develop oesophageal cancer; age is also a major risk factor. In addition, Inzar Gul was from a region where the diet is low in fruits and vegetables; the consumption of red barbequed meat is high, along with hot drinks. These factors acted together to increase the risk of oesophageal cancer in Inzar Gul's case. She had extensive tests to determine how far the cancer had infiltrated the oesophagus, her other organs and her lymph nodes.

She was in such intense pain that she could not even move. She said that when she was told about the cancer, she had gone through the four stages of grief: denial, anger, depression and finally acceptance. She added that the emotional toll was the hardest thing. The cancer had spread and although it would not cure her of the cancer, an esophagectomy would nevertheless be performed. She had had to continue the battle with the disease that had the potential to kill her. She was determined however, to fight the cancer for her family's sake as much as her own.

Just before the sickness, Inzar had been a housewife, a caregiver to her own mother and to a family of thirteen. She had been married off at the tender age of twelve. According to Inzar, before falling sick she was the one holding the household together. However, with the disease and child bearing, she gradually became physically very weak. She could no longer do housework and had little support to look after her children.

On account of the Taliban insurgency in the Khyber Agency, the family had to relocate to Jalozai to a camp settlement. Her spouse was the only wage-earning family member and was a manual labourer on daily wages. The sustenance provided for the large family was complemented by rations provided by the camp. Inzar was an IDP (Internally Displaced Person) who came from an area of great instability, the victim of an insurgency, who had lost her home and all other assets. Additionally, the family was from a most vulnerable category, having to depend on food handouts in the camp for sheer survival. The plight of IDPs is reflected through her case – extreme poverty plunging further into poverty, forced relocation as a victim of conflict, being without permanent shelter; and to add to all these issues, Inzar Gul had to deal with what could be a terminal illness.

She had an incredibly dejected and sad look most of the time. Despite the support, understanding and love of her family, it was difficult for her to bear the pain of the disease. She mentioned that she missed her once normal life of a mother, wife and caregiver, as she was now bedridden most of the time. She said at times she had lost all hope and had given up on life, having mentally given herself a death sentence. She would have gone home without treatment as the family could not afford the cost of treatment, had Heartfile not intervened to support the cost of an esophagectomy.

Sadly, even with a successful esophagectomy, her future health prospects could not be considered positive.

JUMA KHAN - GARBAGE PICKER

This was a disturbing case at many levels. The living conditions and means of survival were disturbing. This sad story illustrates the disparity between classes in Pakistan. We stand on the side-lines watching these people bleed before our eyes. Do we care when the system serves a dastardly purpose, forcing on some, lives ridden with filth, disease and social disdain?

Juma Khan was forced to migrate from North Waziristan to the city of Peshawar and some years later to the outskirts of Islamabad, just to make a living. He was born in Pakistan to refugee parents from Afghanistan and although he had spent thirty-eight years in Pakistan, he bore the mark of a refugee. He was illiterate, had no skills and had adopted the occupation of his parents, who were trash pickers. Born in trash, he lived his life in trash and would perhaps die in trash and be buried in it. No one would ever know that he had existed.

He had been forced into this vilest of jobs; it was his only source of income. His younger brother added to the income of their family of twelve, also as a garbage picker. Juma Khan developed tuberculosis ten years ago and he had assumed that he had been cured when at that time his symptoms retreated. He was not aware of the chronic and progressive effect of the disease. All that was important to him was to continue working to support a large family of seven children, the youngest aged three months, born to a young mother who was infected with hepatitis C and his own mother, also chronically ill with hepatitis C.

He survived by rummaging through trash – rifling through the garbage day after day, while suffering episodic fever, addicted to ‘niswar’. Niswar is the East Asian version of snuff, a type of dipping tobacco that originated from a variant of a dry form of snuff in the 19th Century. It is a moist powder tobacco that is placed under the lip for an extended period of time and is consumed mostly in Iran, Afghanistan and Pakistan.

The look in his eyes reflected the suffering, utter poverty and despair he suffered every day but he nevertheless offered us a seat near his bed as he lay on a blood-soaked sheet and he asked us if we would like a cold drink. We were touched by this gesture from a patient in such pain but this action revealed the spirit of hospitality of the Afghans. In his hard existence, work had taken priority over health; he did not seek treatment for years, until he collapsed throwing up blood and was admitted to hospital. He was suffering from hematemesis (blood in the vomit) which is a serious condition as it causes blood loss and may lead to shock. It is a medical emergency which requires immediate hospitalization.

With hematemesis a patient vomits significant amounts of blood. Khan was diagnosed with cirrhosis of the liver. The test revealed that the latent tuberculosis had progressed from an underlying infection to the active disease of cirrhosis of his liver. He had complained of fever, weakness, loss of appetite and fatigue for years. Cirrhosis is a potentially life-threatening condition with resulting inflammation of and scarring damage to the liver. Khan was told that no treatment would cure the disease or repair the damage to his liver. He was put under observation and administered drugs. A liver transplant was not a possible option as he was not a suitable candidate for this procedure and even if he had been a candidate, the availability of a compatible liver was a very remote hope.

He was weak but wished to share his plight with us. He said that he was not identified or recognized by society, that he had been forced to take up garbage picking as his work and that he had no means or security of any kind. He knew that his occupation was unhealthy and hazardous, always working in filth. He felt that he must have picked up the disease from this work. He sifted through the rubbish, then collected and sold the recyclables.

His occupation had meant ostracism and prejudice, intensified by social rejection. He continued to be treated as an outcast, a refugee and an alien, utterly unwanted. He had often been harassed and threatened by the police and driven away from the garbage piles. Although he was not valued by society, he continued to work in the garbage bins and dumping grounds from morning to evening, seven days a week.

He lived near a dumping ground with no water or sanitary facilities. He felt the pain of having no security regarding his livelihood; he had toiled in the waste since he was four. He

told of a life filled with miseries, a childhood lost and having to survive on a meagre income, unable to afford medical expenses and already under the burden of a heavy loan. He ended by saying that he had little hope of a better future or recovery and that his hospital bed might be his last home before the grave.

Khan's world was as bleak as one could imagine. We witnessed the raw and poignant humanity of this patient barely clinging to life. Heartfile came in to give him hope in a moment of severe distress and was able to bring a slight sparkle to his eyes. We were deeply moved by his terribly tragic story. When and by which governing body will this deplorable condition of its citizens be addressed?

ZIA – AN IDP AND REFUGEE

Zia, a teenage boy, was an Internally Displaced Person (IDP) who sustained multiple fractures of the leg in a motorbike accident.

He hailed from Kargil, an area of northern Pakistan, on the border with India, which came under attack a few years ago. He fled with his family. Deprived of home, livelihood and environment, they inevitably became poorer. This young boy had to migrate to the city for a job to help support his family. He had been employed as a domestic helper in a household for less than a month when he met with an accident.

He was already bearing the psychological and physical scars of migration and exploitation by his employer when the accident occurred and the injuries further complicated his miseries. He was devoid of any expression, apparently helpless to react to this latest uncertainty and pain. At the time of our visit to him, although he was without any attendant or adult family, he was surrounded by other displaced young boys from his area, who gave him what comfort they could. This showed the bond of a strong community. He said that his parents had pinned so much hope on him to support them financially once he was settled in the city but he could not inform them of the accident. They would be devastated.

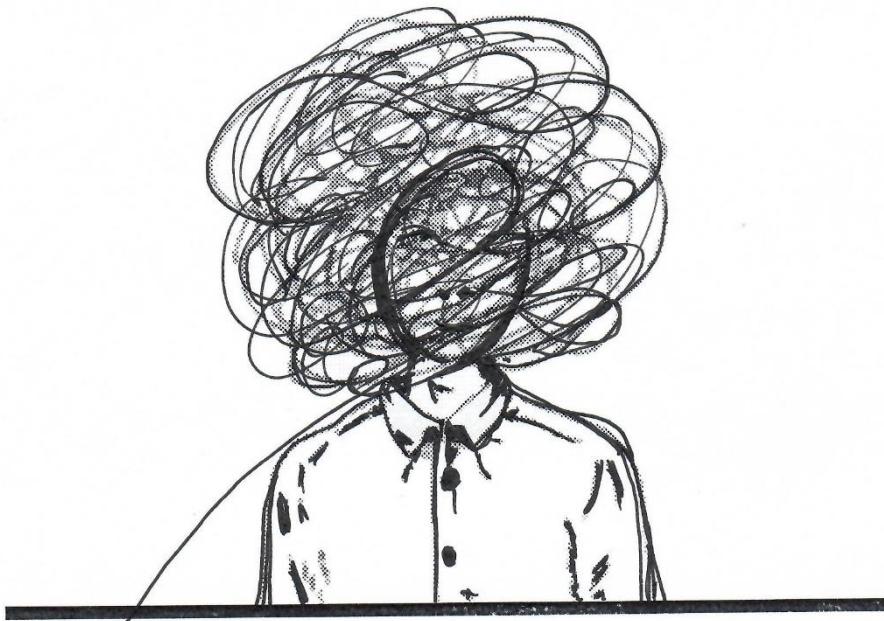
His employer did not show any compassion during this time of hardship as he was treated as just one of many household workers.

The patient was not told anything about the treatment he would need, the implications of the accident, nor about the intervention required for corrective surgery. He said that he would go to sleep with this uncertainty at the back of his mind – he may not recover and thus, could not plan for tomorrow let alone any future beyond that.

Lost and confused he lay on his bed, having been compelled to migrate because of economic reasons but now, far from home he was faced with the loss of his job and poverty growing more acute. He had now been exposed to additional suffering. His socially and culturally alienated status as a Displaced Person and a migrant worker had strongly affected his identity. He said that he depended on help from Heartfile and had no way of knowing what his situation would be from one day to the next. He was left unable to even imagine hope and was in total despair over being confined to a hospital bed. It is here that Heartfile came in and made a difference, providing him with financial support for the surgery and the rehabilitation he needed.

In this case it is important to highlight the intractable struggles that so greatly influence the lives of people who flee conflict situations which so strongly afflict already poor people with the staggering stress of displacement – the loss of family and friends and the disruption of social support networks. The impact upon so many dimensions of physical and mental health is enormous. When will there be access to permanent homes for Internally Displaced Persons?

Terminally Ill Patients



The fifth category of accounts focuses on Terminally Ill Patients. In many cases the treatment options were limited and other procedures were unlikely to be curative. Ethically, the patients once referred to Heartfile were supported in spite of negative prognosis. The agony of not only the terminally ill patients but also their care-givers is depicted. The sense of deprivation and the deeply personal pain the terminally ill suffer are strongly felt in these stories. Treatment simply prolongs life without addressing the issues related to the basic dignity of the patients.

ARSALAN – TERMINALLY ILL

Arsalan: a two-year-old male child was presented to Heartfile with a month's history of progressive distension of the abdomen and low-grade fever. For the last twenty days he had also exhibited swelling and puffiness of the face and feet and had been vomiting off and on. There was decreased appetite and the family noticed that he had developed profuse night sweats during the last fifteen days. He was visibly very sick and weak.

Arsalan hailed from a very distant, small village, Dirkot in Azad Kashmir, where there was no available health care facility. The little child was carried for miles, partly on foot, to the nearest hospital in Bagh and he was later referred to the Oncology Department of the Children's Hospital in Islamabad. He was diagnosed just before his second birthday with leukaemia. A request for an immunophenotyping test was sent to Heartfile. The test is a process used to diagnose specific types of leukaemia and lymphoma by comparing the cancer cells with the immune system. The test helps guide treatment by detecting and evaluating residual cancer cells.

The family and child had to relocate for treatment of the lymphoma. Lymphoma is a cancer of the lymphocytes. These tiny cells are supposed to be of assistance to the immune system. When a lymphoma develops, the cells tend to lump together and the lymphoma appears as a tumour. This tumour is often attached to the lymph nodes, which can be found on the sides of the throat and at other places in the body. Lymphoma is a difficult disease to catch in time because the symptoms are vague and often seem unrelated to each other. Like many cancers, lymphoma can be treated with chemotherapy to lessen the risk of the cancer returning to the body. Bone marrow transplant and radiotherapy are alternative treatments.

The child needed immediate treatment but there were serious financial constraints in the way. The family had been affected by the earthquake in 2005 and had lost all their assets and home. They lived in a mud house without any safe drinking water or sanitation. Arsalan was one of eleven dependents of a father who was a daily wage earner. There was no way that the family could afford the treatment which was costly, complex and long term. As it

is, treatment options in Pakistan are poor and limited, primarily owing to financial constraints, lack of trained paediatric oncologists and proper supportive care. Late diagnosis and detection contribute to advanced stage presentation and poor prognosis.

The disease had taken its toll prior to the test being administered. Infection and malnutrition had added to the morbidity in Arsalan's case. The family was completely illiterate and so was not equipped to understand the seriousness of the illness, nor how to recognize the serious symptoms.

Normal life for the child came to a sudden halt and a great feeling of helplessness weighed on the family. At such a young age he had been battling for his life. Thin, tiny with tears of pain in his eyes, Arsalan was lying on a hospital bed seriously ill, as he had been for much of his short life. The despair and misery of his mother were overwhelming. Arsalan represented such concentrated agony of human existence and desolate poverty. Was it the last stage of his short life's voyage? It was the tragic sight of a hellish experience of life. His energy had been drained by the disease and he lay there listless. Their child being possibly terminally ill and afflicted by an incurable disease that could drag on for years, could be the ultimate of endurance for the poor family. Arsalan's life seemed to have reached its end before it began.

This was one of the unfortunate cases, where Heartfile took a patient into its fold, hoping to support treatment for some time, but the patient succumbed to the illness and the need for funding sadly ceased.

HAROON – A CASE OF LEUKODYSTROPHY

Haroon's breathing was obviously difficult. The child was listless much of the time and clung to his mother. He had an empyema and was admitted to the Intensive Care Unit of a hospital in Peshawar. Haroon had lost all immunity and there was pus in his chest cavity. The child looked very distressed; he had a long history of seizures, shortness of breath and cough that had become aggravated during the previous two months.

The parents said Haroon had been a vibrant, bright and articulate little boy. At the age of two, his mental and physical development slowed down. He began to exhibit slight problems with his balance. He did not run quite like the other children of his age. He appeared well but the family noted that there was a gradual decline in Haroon, a progressive loss in body tone, movements, gait, speech, ability to eat, vision, hearing and behaviour. This slowing down in his mental and physical behaviour was obvious. The symptoms were difficult to connect to any specific disease.

An MRI revealed that Haroon was suffering from leukodystrophy. It was devastating news for the parents. They were told that their little boy, who had been so full of life and love, was slowly losing his capacities and would most likely not survive childhood. For them this was inconceivable but they slowly recognized its inevitability as Haroon's symptoms worsened. Haroon's immunity decreased, and he developed empyema.

Leukodystrophy is a rare neurological disease which affects the cells of the brain, nervous system and spinal cord. Little is known about the condition. It is an inherited, progressive, and degenerative disease. Haroon's 22-year-old aunt and younger sister tested positively for the same condition. The family was told by the attending doctor that they must be supportive and that only the symptoms could be treated. Such treatment may include medication, physical, occupational and speech therapies and nutritional, educational and recreational programs. It seems that bone marrow transplantation was showing promise for a few leukodystrophies. Haroon was much too poor for any of these treatments and programs.

The family wondered what sort of future awaited Haroon. Since this condition was degenerative, all of his abilities would be affected: intelligence, speech, his senses of hearing and smell, as well as his vital functions. When all of his systems failed, death would inevitably follow. For the parents it was heart-breaking. Haroon was one of fifteen dependents of a father who was a poorly-paid village schoolteacher. It was already stressful to be poor. The impact of Haroon's illness was enormous: the father had to be on long leave without pay. The illness forced the family to sell all their assets. Haroon had to give up school at the age of four. Illness and poverty went hand in hand for the family and with the depletion of their assets, the family found themselves trapped. The family income had drastically decreased and Haroon's father had also borrowed beyond his ability to repay for the treatment. The debts meant the family was pushed further toward multigenerational poverty. The parents were devastated. Haroon's existence had been a journey of dealing with life amidst suffering. Beyond his own great physical suffering, his life had entailed the sacrifices, loss of hope and suffering of his parents.

Heartfile supported the cost of a decortication procedure which was to be performed once he was more stable. The ethical aspect intervened related to financial support, although the prognosis was far from positive. There was not much of a chance that the child would survive but for the little time he had, he was provided with as much comfort as possible through Heartfile's financial support.

HUSSEIN - CANCER OF THE EYE

Retinoblastoma is one of the most common childhood cancers and one of the most curable. It starts in the retina, the very rear of the eye. The eye has cells called retinoblasts that divide into new, light-detecting cells. Some retinoblasts continue to grow rapidly out of control and form a cancer known as a retinoblastoma. 20% of the children born with this abnormality inherit it from a parent. If not treated, the tumour can continue to grow and may fill much of the eyeball. In addition, cells may break away from the main tumour on the retina and float through the vitreous tumour to reach other parts of the eye, where they can form more tumours. There is always the danger of loss of vision in the affected eye.

This disease was diagnosed in the case of Hussein, aged 5, before it had spread outside the eyeball. Hussein had developed only one tumour in one eye. He was cross-eyed, a condition called 'a white eye', and he complained of pain in the affected eye. His vision became increasingly blurred and his pupil in the left eye appeared enlarged. He was from a small village in the region of Skardu in the northern area of Pakistan where access to health facilities is lacking. His father had to carry him miles on foot to the local government hospital in Skardu. He was immediately referred to the Pakistan Institute of Medical Sciences (PIMS) for further diagnosis and specialized treatment. He was admitted to the Oncology Department of PIMS Children's Hospital in Islamabad. Hussein's mother was deceased: he had only a father who was a manual labourer, the single parent of six young children. His father was illiterate and primarily concerned with earning a daily income to provide for his children. He did not notice the white mass in the pupil of Hussein's eye until his child started crying and complaining bitterly of pain.

Hussein's father said that he did not know what the future would hold for his son. The death of his wife had been a disaster in his and his children's lives and he said that it had been challenging to cope with caring for his children, work, housework and the inevitable emotional overload. As a single parent he felt lonely, anxious and depressed even before the complication of Hussein's cancer. This trauma added more difficulties for the father in that he was forced to realize that he was unable to meet the costs of treatment for Hussein, for

the necessary relocation with his son for medical care and the complicated issue of care for his children who were left behind with neighbours in the village. Both father and child had already become invisible to the community due to both their poverty and the family situation. The child sitting on the bed in the hospital, with his diseased eye bandaged, was sharing a breakfast of dry bread and tea with his father. The father was so desperately poor that he could not buy himself a meal and depended on sharing with his son the meals provided by the hospital. The father was in a state of shock and articulated his plight slowly. It did not seem that he had been briefed by any of the hospital staff about the nature and seriousness of Hussein's ailment. He was both confused and distraught.

Fortunately, the case of Hussein was diagnosed early enough. The tumour was advanced yet the eye could be treated. The reality is that cancer is always a frightening diagnosis and when it affects children, the situation is often overwhelming for parents even when they are well-informed. It was a challenging and tragic situation; the prospects for a future for Hussein were bleak. The medical treatment would be long term. This family would have extreme difficulty in coping with and managing a long term illness. The father might not be able to return to his work in the village as his efforts for Hussein's survival became his highest priority. The illness of the child would further ensnare the family into poverty. The larger economic impact involved the neglect of the other children, the cost of relocation and health care, in addition to the reduced income due to working days lost while caring for Hussein. The father might also be marginalized from support services.

The case was referred to Heartfile for support, which was, of course, approved. The family's poverty was so obvious that an additional amount was provided to the father as a grant, so he would be able to buy food during his stay in Islamabad while attending to his son.

Hussein and his father left a long-lasting image of innocence, helplessness and suffering. We are privileged to have played a small part in alleviating their suffering.

IKRAM - THE SEVEN-YEAR-OLD

Ikram was a young lad of seven sitting on a bench by the bed allocated to him in the hospital, barefoot and unattended. He could not lie down. He did not respond when we talked to him. We wondered whether he could not talk at all as he had blank, uncomprehending eyes. Discomfort and pain had reduced him to a lifeless existence. He complained of a severe cough, problems with breathing and constant high fever. The symptoms were ignored by his parents but they got worried later as the symptoms worsened over time. Ikram lost weight after losing his appetite.

Ikram lived in a small village in the mountains of Azad Jammu and Kashmir. He was taken to the local government hospital of Kothli where he underwent tests and X-rays and was later moved to Muzaffarabad Government Hospital. On account of further complications, he was referred to the Pakistan Institute of Medical Sciences for further investigations.

He was the youngest of eleven children of a father who was a labourer and a mother who was a housewife. He had a brother who had a heart condition, whose medical expenses had to be paid for out of his father's small wage. The father's income depended upon the availability of labour in the area and was thus irregular. The family had already taken loans worth Rs.50,000 from various relatives to meet expenses incurred so far. This clearly indicated the extent and burden of their poverty.

The case of Ikram was referred by the treating oncologist to Heartfile for assistance with the cost of his tests. Within a day, Ikram's case was processed through a face-to-face conversation with his parents. The details were put in the system, a patient assistance meeting was held during which the assessment was carefully scrutinized. The verifiers had to justify each aspect of the assessment in front of a panel which included Heartfile's finance team. In this case full assistance was approved. The father and doctor were immediately informed of the decision so that the tests could be done. The process, through electronic tracking and time stamping, enables Heartfile to process requests, provide services and manage funds with transparency, tractability and speed, all supported by a team of sensitive and principled staff.

It seemed as if Ikram would need a bone marrow transplant which would involve long treatment and additional financial costs.

The impact on this poor family was enormous – that of poverty, dislocation, uncertainty about the recovery and the increased debt burden. This was the case of a most deserving patient, young boy, from a large family and from a distant location where no hospital facility existed and thus, no treatment was available. Ikram was lucky to be referred to PIMS and to Heartfile. The long process of bone marrow transplantation began — Heartfile committed to financing the treatment all the way through.

SAQUIB - FROM MALAKAND AGENCY

Saquist, a twelve-year-old child, looked deeply into our eyes, his expression pleading. His father was in tears but we kept on reassuring him as best as we could. He and his son had been making numerous daily trips from a distant village in Malakand Agency to Islamabad.

Saquist has been diagnosed with severe aplastic anaemia. The stress of fatigue and of poverty was so obvious in his appearance and expression. This child needed a bone marrow transplant and was referred to Heartfile for financial support to carry out the initial diagnostic tests.

We felt the pain of Saquist's father as he gazed through us. He knew something we have never known, the pain of witnessing his child suffering and dying, if not treated, perhaps a slow and painful death. The despair in his gaze informed us that his pain would not be alleviated, that for this father already shaken, bruised and uprooted, the misery would remain.

Saquist's little feet had trod the shifting ground, always in pain, yet he continued to be dragged back and forth in search of treatment. He was not an apparition, but a simple child with an extraordinary father. We were able to see the spirit, the pain of a father and son and we felt a nearness to them. "Life for me has not been a smooth path." These words expressed the father's difficulties in life and yet he was ready to carry on with the struggle. By sharing some of his hardships, he taught us a great deal about survival, strength, dignity and love.

Saquist was the youngest child of a family of ten and came from a poor family. The father was in shock and did not comprehend the severity of the diagnosis. He said that his child had the support of the family and that they had rallied round him. The diagnosis had brought both parents closer to the child.

Saquist was suffering debilitating pain, constant fever and loss of appetite. He had bruises on his arms and experienced nose bleeds. He was taken to the local dispensary and later to

a private hospital in Peshawar. The pain, it turned out, was caused by chronic aplastic anaemia. It develops in the bone marrow and causes a genetic abnormality.

It is a condition in which the marrow fails to produce blood cells. The child had already been greatly taxed physically by the harsh regular commute from his village to Islamabad and the cost of the recent medical intervention imposed a significant financial burden on the family.

Saquib had been undergoing weekly blood transfusions for the past six months. The transfusions were only meant to be a temporary solution until his condition stabilized but there were no signs of its doing so. After this diagnosis, a search was made by the treating doctors for a bone marrow donor to provide a permanent treatment for Saquib's condition; so far it had been without success.

Poverty became a major obstacle to the treatment. The father had searched numerous hospitals to find affordable treatment for his son. He was forced to turn to charity for assistance. It was a long wait. An application to Bait-ul-Mal was rejected as the existing funds of the organization were already in use for a political campaign by the party in power. The treatment would require a complex series of analyses which was costly and long term.

Heartfile supported the diagnostic tests, which were essential to identify a donor for bone marrow transplantation. Once, identified, Heartfile would support the bone marrow transplantation as well. The dilemma of the father was whether the child would be cured at all. "I never thought that I would say that my son had a life-threatening disease. This is something no parent ever wants to hear. I cannot believe this is our plight. I have lived through terrible situations but never have I come close to one like this."

SAYED MOHAMMAD ZEESHAN ALI SHAH - MULTIPLE MYELOMA

Life had collapsed. Zeeshan's life had changed from being an active student to a helpless, weak and frail patient lying on a bed in a room which he shared with three other patients, in a state-of-the-art centre for bone marrow transplantation.

This centre had staff with significant experience in the treatment of cancer and leukaemia and was the most modern and well-equipped centre of excellence in providing bone marrow transplants in Pakistan.

Zeeshan was a healthy individual until early May 2012 when he developed fever, bruising, and dizziness, along with shortness of breath and extreme fatigue. His condition continued to deteriorate; he was admitted to Shifa International in Islamabad, a private hospital where he was diagnosed with acute myeloid leukaemia.

Acute myeloid leukaemia (AML) is a cancer that starts inside the bone marrow, the soft tissue inside bones that helps form blood cells. 'Acute' means the disease develops fast. This type of cancer is rare under the age of forty. Zeeshan was only twenty-two.

He stayed at Shifa for five days and it cost the family Rs. 85,000. He was then moved to Lahore to Shaukat Khanum Hospital, a move which cost another Rs. 20,000. Here the family was informed that the hospital only treat patients under the age of 19 for bone marrow transplants. Following this, he was referred to a hospital in Rawalpindi where he had been since 6th June, 2012. The family had taken a loan of Rs. 500,000, an amount which they had to deposit for the treatment to be initiated. Zeeshan was being given chemotherapy to kill the cancer cells and blood transfusions to keep him alive.

The treatment was mandatory as his condition was critical. The reality which faced Zeeshan was harsh. To be blunt, it all came down to money. He was told that the disease was a fast-growing cancer of the blood and bone marrow. He underwent an X-ray and an ultrasound of the abdomen to find out if the leukaemia cells had spread outside the blood and bone marrow.

Zeeshan also stated that he had a lumbar puncture (spinal tap) to find out whether there were leukaemia cells in the fluid around his brain and spinal cord. All these investigations required unaffordable financial expenditure.

The cancer journey for Zeeshan had been a brief one and very painful. He said that living with cancer was extremely dismal with no future. The condition made him feel alone but he knew he was not as his family was near. The thought of the disease ran through his mind relentlessly and he was still deep in shock over the diagnosis. Nevertheless, he said that he would battle this disease that had the potential to kill him. He said it was awful. He missed his once active, normal life because he was now bedridden. At times he lost hope and felt like giving up on life. He was fearfully concerned about what the future would hold for him.

Zeeshan was the eldest of a family of five on whom much hope had been placed. All the aspirations of this family were pinned on Zeeshan – what they had not been able to achieve, they dreamt of achieving through this promising student. His father had a heart condition while his mother was a chronic diabetic patient. The family were internally displaced (IDP) victims of the 2010 floods and had moved from Nowshera.

They had lost their home and all their belongings and moved to the outskirts of Islamabad in search of livelihood and shelter. Fortunately, they were given the refuge of one room by a local estate developer and in return Zeeshan, being a very bright student, was able to provide private tuition to the four children of the landlord. The family was content with this arrangement and paid the monthly utilities. Zeeshan's father was a transport supervisor supporting his family of five, his elderly father, a disabled brother with his spouse and three minor children and a divorced sister all of whom were still in the ancestral village.

The approximate cost of the treatment would be around Rs. 40 lacs. The family had no financial means. Any amount would be beyond their capacity. The evidence was clear in this case between adverse health and chronic poverty. Poverty had bred ill-health and ill-health was keeping the family poor. Absolute poverty and no safeguard against the ailment had complicated the situation and caused Zeeshan to fall into this trap.

Zeeshan's case reflected the trials and tribulations, the plight and dilemma of the worst nature. He wondered whether the treatment would save his life or simply delay his death. He stated that he had mentally given himself a private death sentence. He kept on thinking to himself that there was no way he could get out of this situation alive. On the other hand, he was determined to fight and win the cancer battle not only for himself but for his family; he did try to develop a positive outlook on life and his future at times. However, the despair, the uncertainty of any future and the fear were apparent as Zeeshan shared his story.

Heartfile supported part of the expensive treatment in spite of being told that the disease was incurable. Heartfile is bound by the ethics and principles that as long as there is life, hope is to be maintained and so the organization came up with a substantial amount.

Zeeshan was hospitalized from 6 June to 23 July. On 22 July he wanted to go back home but remained in the hospital as he felt unwell. He had wanted to return home as he felt the end was very near. At this stage he felt life had no meaning and wished only to be released from the pain. He wanted to spend his last moments amidst his loved ones. However, this was not to be, as death came unannounced. On that same night his father visited him and Zeeshan said a final goodbye to him. These were Zeeshan's final words: 'Father, while you leave do not look back at me as it would intensely anger me and leave feelings of bitterness and unfairness of a life unfulfilled.' On his return home the father understood that the hour of demise was near and immediately sent his wife and daughter to say farewell to Zeeshan. When he saw his mother Zeeshan wanted to talk to her but was too weak to do so. He died on 23rd July at three in the morning after 45 days of hospitalization.

The parents were interviewed two months after Zeeshan's death and they expressed immense despair and pain at their loss and stated that a part of them had died with Zeeshan,

that this death had changed every aspect of their life and their willingness to continue to live. His death had created an enormous emptiness. They had not only lost an adult child but a close friend and an irreplaceable source of emotional and practical support. They were still grieving the loss of all the hopes and dreams they had had for their child.

They said they would always grieve over the potential that would never be realized and the experiences that they would never share. They added that a future had died along with Zeeshan. The family had fought every battle seeking a cure of the cancer and were deep in debt.

They did not lose hope in spite of being reminded constantly by the treating doctors that there was no hope whatsoever of a cure. They had been in a state of intense shock, disbelief and confusion until the night prior to Zeeshan's death. The mother said that she still wakes up every morning thinking it is just a bad dream but soon she realizes that her world has fallen apart. She had enlarged photographs of a healthy and vibrant Zeeshan and they reflected the special feelings that the family was keeping close. The photograph served as a reminder of a beloved child with memories of a joyful life but also the reality of the subsequent suffering he endured during his short but painful illness.

The family further shared that periods of intense grief come and go. The waves of grief were all too intense and frequent and they realized that these feelings of sadness and loss would remain for life. The father, mother and sister showed their grief differently and here the gender aspect was apparent. The father was trying to control his emotions, to be strong and to move forward. He got more engrossed in his work which presented an escape from grief. The mother and sister cried openly and wanted to talk about their grief. They said that they were surrounded by constant reminders and that their job as caregivers had abruptly and so tragically ended. Nadia, the sister, stated that she had lost not only a sibling but a confidant and a life-long friend.

The death of Zeeshan compelled the parents to rethink their priorities. They would return to the village to re-engage in life and take care of the rest of the dependents as the purpose of being in Islamabad was only for the sake of Zeeshan's future and his further studies. His legacy would continue after his death. The memories of joyful moments spent with Zeeshan

and the love the family shared with him would live on. These reminiscences would always be part of their lives and the family would continue to battle to cope with the deeply devastating and disastrous experience.

Amidst all that they shared, their gratitude to Heartfile, for having supported them at a critical time in their lives was clearly evident. I was deeply moved by this case.

SHAD NAWAZ - FROM LAKKI MARWAT

A thirteen-year-old son was the care-giver for Shad Nawaz, a man of forty-five who hailed from a small village near Lakki Marwat. The boy was the eldest child in the family but the youngster looked lost and distracted by the responsibility of caring for an ailing father in an unknown and intimidating environment.

The patient had been a chronic smoker since an early age and was suffering from emphysema, a chronic lung disease which, in his case, had been caused by exposure to years of tobacco smoke.

Emphysema is a long-term, progressive disease of the lungs and is a condition in which the air sacs of the lungs are damaged and enlarged, causing breathlessness. An X-ray showed that his lungs had become inflated. The treating doctor decided on surgery to decrease the lung volume and help maximize the function of the remaining healthy lung tissue.

This illness was a result of the sad but true-life experience of Nawaz and was directly related to his poverty. He said that he never realized that smoking could destroy his future. He was having problems breathing, constantly had a fever and had felt an increasing weakness for the last few years but he had never sought medical advice or treatment.

Nawaz's whole life had changed. He had gone from being a person who took care of a household of thirteen to someone completely incapacitated. He had hardly recovered from the grief of recently losing both his elderly parents, who died within an interval of six days and from recuperating from typhoid. He had been in every way a responsible son to them. He had relocated from his home to Islamabad to earn a livelihood as a driver. He then returned to the village to take care of his ailing parents after having recovered from typhoid.

Nawaz had hardly been able to cope with the loss of both parents when he was suddenly rushed to Lady Reading Hospital in Peshawar and was diagnosed with this deadly disease. He had watched his health worsen and he was now struggling for each breath. He had not

been able to work for the past six months due to typhoid, and thus he had earned nothing. In addition, he had been compelled to take loans from numerous individuals to meet the costs of the treatment for his parents, the expenses for their funeral rites and the normal household expenses and the cost of his own treatment.

Being the eldest brother, he had, additionally, the responsibility of his two, young, widowed sisters with their five young children. He appeared to be a very progressive individual because he respected the choice of his sisters to remain single and not be forced into getting remarried. He said that he would protect them from the social stigma of widowhood and support them in living a life of respect and dignity. What an exceptional man from such a region of rigid rituals, traditions and customs, where women are invisible. The illness had a staggering impact on the family. Nawaz stated that he feared the disease might progress into lung cancer and his death.

Lung cancer and emphysema are two distinct diseases that cause damage to the lungs. Emphysema does not, however, lead to lung cancer. The relationship between these diseases is instead one based upon mutual risk factors, namely smoking. A person with emphysema is ultimately at greater risk of developing lung cancer. This is because smoking complications can extend from lung tissue damage (emphysema) to lung cell damage (cancer). Nawaz was told that there was no complete cure for emphysema and that the procedure and medication would help him but would not cure him. It came as a great shock when he realized that medication would simply make existence a little more comfortable while waiting for death.

As Monya Baker writes in her 'Panoramic View of Lung Cancer', "Lung cancer causes more deaths than any form of cancer. About 1.6 million people worldwide are diagnosed with the disease each year, with fewer than 20% still alive five years later."

Nawaz had always been poor and had suffered emotionally, physically and financially from the limitations caused by poverty alone. He had taken care of everyone in the family in the past. He was their strength, the source of unconditional love, inspiration and hope for all the family. He and his family had been hit by grief and sickness over and over again. In spite of all the hardships and sorrows, he remained the rock and the anchor for the family.

The law of inheritance in Islam grants two thirds of everything to males in the family and it was justified in this case as this patient was giving protection and shelter to his widowed sisters and dependents. This patient, who carried the heavy responsibility of caring for his parents, his own family and his extended one, like many other practicing Muslims, lived below the poverty line. Facing a crisis such as this, the choices before him were stark.

If he did nothing because he could not afford to get treated, he would die. He had therefore, taken loans and was facing lifelong debt. He had already suffered extreme poverty for months. Would he go home after the procedure with needed supplies of medicine, or at least good instructions on how to manage self-care, as there are hardly ever any discharge or recovery instructions? As it is, the public health care systems that exist in Pakistan are simply not enough to meet the demand even for ordinary health care, let alone for the specialized care which Nawaz required. It is here that Heartfile came in to make a difference, by picking up the cost of this specialized care.

SHERAZ - THE DEADLY STRICTURE

A common cause of breathing trauma in children is oesophageal atresia which is a congenital condition characterized by failure of the oesophagus to develop properly. It is also known as oesophageal stenosis. Oesophageal dilation offers potential relief and healing for those suffering from oesophageal stricture, but it was not to be for Sheraz.

Five years old, Sheraz had been unwell since birth and had been very sick since he was two. He experienced severe and progressive dysphasia (difficulty in eating) that worsened. He had not been able to eat any solids for two years, had been vomiting and had abdominal and retrosternal cramps that lasted several months despite various treatments.

This disease had struck the young child from a very poor background with an ill father and a mother who had just given birth to a fifth child. Sheraz' father could not cope and they had to depend on charity and the support of relatives. The father was also unemployed and under severe debt and liabilities. The child would not have been treated if he had not been referred to Heartfile for support. He could not breathe, was in great pain, and had not had proper medical treatment for the past two years. He had endured acute suffering and did not have the comfort and security of his mother.

What care did come was largely given by his grandmother and his uncle. The harsh and grim realities in which the family was mired meant there was little money or time that could be spent on him. The elderly grandmother had difficulty in handling Sheraz. She said that taking care of a chronically ill child was one of the most draining and difficult tasks she had ever faced. Beyond coping with physical challenges and medical needs, any caregiver had to deal with the emotional needs of the child. The impact of Sheraz' sickness on the family was overwhelming.

Initially a conservative treatment through dilation was administered but this was considered a temporary solution only. Oesophageal dilation offers potential relief and healing for those suffering from stricture. But in Sheraz's case, it was not successful. This

failure resulted in the necessity for operative intervention, which was supported by Heartfile.

Sheraz' condition worsened despite every attempt by doctors to help him. A cure was not possible as the illness was too severe. During his last days, his caregivers could only try to make him more physically and emotionally comfortable and as free from pain as possible. The unfortunate child was destined not to recover from the illness that had lasted his entire five years. This had an unbearable effect on the family.

The illness turned out to be terminal. Perhaps medical treatment simply extended his life. There was always an overshadowing fear that the final outcome would be death. His case was assessed on 16th January by Heartfile; he was operated on 1st February and died on 2nd February. It was nearly impossible for the family to relate in a realistic way to both the hope of a cure and the possibility of death. The death of Sheraz was a tremendous burden which intensified the challenges of everyday life for the grandmother and uncle. It was a most painful and debilitating loss.

They had witnessed Sheraz' pain and agony, then life had drawn to a close at the age of five. The bereaved attendants experienced grief, depression and sadness as well as loneliness. As painful as it was for both of them this pain remained part of their memory of Sheraz; they felt also that there were indeed precious memories that they would not wish to give up.

However, the grandmother said that part of her and a part of the future died along with Sheraz. "My job as a caregiver has abruptly ended and I lack the will and purpose to continue living." This is the sad truth for a grandmother who spent years caring for a child with a terminal illness.

She added that Sheraz' legacy remained with them after his death. It was a legacy of pain and suffering that had resulted in an enormous emptiness. Life changed for both the survivors as they continued struggling with the grief and great uncertainty about the future. The sadness, fear, hopelessness and overwhelming despair over the loss of the child would remain with them forever.

SYED AHMAD SHAH - LUNG BIOPSY

Syed Ahmad Shah, a 30-year-old father, came with a six-month history of progressive breathlessness and chest pain on his left side. He had also felt increasing pain and swelling in his joints. He reported no significant past medical history and was not taking any regular medication. He had been a smoker in the past and had worked as a carpenter but had not been exposed to any toxic elements. He went to the emergency department of a local hospital in Peshawar and was diagnosed with acute pneumonia and an associated pleural effusion.

Pneumonia is inflammation of the lungs. It is one of the most infectious diseases. Ahmad had delayed seeing a doctor. Pneumonia needs to be treated by medical professionals at the very first occurrence of symptoms and even then, may prove fatal. Intravenous antibiotics were administered and a pleural effusion tap was performed. Testing of the pleural fluid did not reveal any malignant cells. Following the pleural effusion, Ahmed improved and was discharged.

He returned after a week with worsening dyspnea (shortness of breath) and vomiting; he was admitted for further investigation. A chest X-ray revealed re-accumulating pleural fluid and a large pleural mass involving the left thorax. A CT scan confirmed a large left-sided pleural mass with an associated effusion and mediastinal shift. An open lung biopsy was planned to ascertain the nature of the growth and further treatment was projected. It is to be noted that an open lung biopsy is an invasive procedure, has low specificity and hence is not advised routinely; however, the patient was being treated by a competent team of surgeons.

A look of utter hopelessness was on Ahmad's face although he was receiving a high standard of care regardless of his poverty. Poor people cannot usually access skilled medical care but Ahmad was fortunate in being treated at Lady Reading Hospital and being supported by Heartfile.

The physical agony was immense as he battled the ailment. He said, “I do not know if it is destiny. I find myself at a loss to describe how I am suffering. The immediate dilemma is how to get the required amount for the treatment. My family has been torn between surrendering to fate and crying out for support. For a long time, I have been struggling to meet my family’s requirements to foot the bills for treatment and the cost of medication has now become something I cannot bear. Life has become misery. How can I be suffering from a life-threatening disease like cancer? Nobody is able to ease my anxiety. The disease has robbed me of my ability to function. I dread the coming of every single day as it signals further suffering. I long to live a life without pain. Now that I am sick, I realize the value of a healthy life.”

Due to his poverty Ahmad had earlier given up on the idea of getting treatment. His priority was not his health, but to contribute to the income needed to support a joint family of twenty. He said, “I grew up in a very poor family and it meant there was never enough to go around. I wanted to take measures into my own hands to better the financial situation. I started working at a very tender age. Work was difficult but I am grateful as it helped instil a strong work ethic and resolve in me.”

While sharing his trials and life experiences, his attention dissipated into a fog of pain and exhaustion. The uncertainty of battling the disease and surviving was strongly felt. Poverty and disease are common enemies for men like Ahmad and need to be fought against. Enormous efforts must be made to improve the wellbeing and health of Pakistan's voiceless and poor patients.

Victims of War



Victims of War constitute another category of those who suffer. The direct violence of warfare has an immediate impact on physical and mental health. The effects of war, besides the initial casualties and injuries due to weaponry, bring long-term suffering with enduring effects on the wellbeing and lives of populations. Furthermore, war leads to the collapse of medical facilities and as the stories show, patients have to relocate in search of treatment at a very high cost.

BURHAN UDDIN – A REFUGEE

Burhan Uddin, an Afghan, was married with children but was also the head of a household that included five siblings between nine and fifteen years old. They had been orphaned and he was left with the responsibility of looking after his brothers and sisters. He appeared helpless, distraught and isolated in an environment foreign to him, surrounded by a language unknown to him. His anxiety was more for his family at home than for identifying the cause of his serious ailment. Burhan Uddin was suffering from cancer, a devastating disease. He said that he did not want to die but that he wanted to see his siblings and his spouse and children taken care of, when he was no more.

Due to his sickness, he was no longer able to work. The lack of financial means and absence of a support system intensified his anxiety. Relocation to Pakistan for treatment was mandatory as his ailment had not been diagnosed in his nearest city, Jalalabad, in Afghanistan. Burhan was a well-respected individual in the village and was also known in the city. He shared his worries with an acquaintance who fortunately had family in Peshawar and he decided to go to Peshawar to seek medical assistance. He took a loan to bear the cost of travel and relocation. He was received by the family of his acquaintance on arrival in Peshawar and was admitted to the hospital. They had been constantly attending to him so he had indeed been fortunate in this respect.

In the hospital the X-ray and CT scan revealed cancer of the oesophagus. He wondered whether he could be cured or if he would be condemned to death prior to a further drop in his quality of life. He had wished his disease had been detected at an early stage. According to medical literature, success of the treatment is rare. Defenders of surgical treatment argue that resection is the only treatment to offer the chance of a cure, whereas defenders of a non-surgical approach claim that oesophagostomy has a prohibitive rate of mortality and that oesophageal cancer is an incurable disease. The treatment plan for Burhan was an oesophagostomy which Heartfile had been requested to support and did.

Burhan was lucky to have been assisted by a referral to a support system in Pakistan. Here one finds the bonding of a community that in times of adversity is of great help. He had one person, he said, a relative of an acquaintance in Afghanistan, with whom he could share what he was going through and he felt comforted and reassured by that presence. He further added that he shared a special connection with his attendant in his despair and sorrow. He said he had learned through his suffering to be patient, to find inner peace and perspective in his heart. He constantly tried to show strength and hope. He said that through his fight with the disease, he was motivated to continue living a life that consistently required great courage; that for the sake of his family there should be nothing to prevent him from overcoming this suffering.

He underwent the procedure and was sent home. Here numerous questions arise about post-operative treatment such as chemotherapy or radiotherapy and the financial cost of these. Should he return to Afghanistan or remain in Peshawar? In Afghanistan the civil war and the Taliban's reign have left the already dysfunctional health system in tatters. However, a surgical procedure alone is not sufficient to eliminate the cancer. The follow-up treatment and support of the patient are crucial. Furthermore, this was a patient who was also afflicted by abject poverty, one who lived in a war-torn country where health care for the poor is inadequate or inaccessible.

SHENA - FROM KHOST

Shena, was born with a congenital heart defect. Congenital heart defects are abnormalities in the heart's structure that are present at birth. Approximately eight out of one thousand babies have congenital heart defects, which can range from mild to severe. The defects happen because of incomplete or abnormal development of the fetus' heart during the very early weeks of pregnancy. The cause of most congenital heart disease is unknown.

Shena's case required a surgical intervention. She hailed from Khost in Afghanistan. Throughout her first fourteen years she was never in good health but was without specialized treatment, although she spent her childhood in and out of hospitals, undergoing treatment for minor ailments.

One factor responsible for the high rate of this disease is the prevalent custom of consanguineous marriage. Shena's parents were second generation first cousins. The disease is strongly hereditary in nature and the death toll rises as first cousins who marry pass these genes on to their offspring. Afghanistan lacks trained cardiac surgeons and qualified doctors who are capable of attending to these cases as well as the proper equipment to diagnose them.

Shena's haunting eyes and direct gaze would captivate any onlooker. Her gorgeous eyes haunt our dreams. She was indeed a magnificent beauty. Her eyes were wild, her smile rendered her beauty more intense. She was vibrant and sweet. However, these eyes expressed both pain and resilience, strength and beauty.

Like many little girls, Shena must have dreamt of playing. As her condition deteriorated, she was deprived of a normal child's life of eating and playing outside. The family was simply devastated, anxious about Shena's immediate and long-term health. They did not know where to turn for support. They knew they could never earn the astronomical amount the child's surgery demanded. Years rolled by and they accepted her fate until one day the grandfather decided to give it a try after having been advised to cross into Pakistan for

treatment. They bought the tickets with borrowed money but failed to seek treatment in Pakistan as they had already depleted their funds and they could not afford to pay for the necessary surgery. The family then returned to Afghanistan.

Shena's father, a poor Afghan labourer, beaten down by poverty, had emigrated to Dubai in order to support a family of twelve. Shena said that she had not seen him in years and missed him. She said that she lived in one of the poorest and most squalid areas of Khost – an area in which poverty stalked in its most hideous form. The joint family of twelve dwelt together and survived as best they could, depending on the income sent by Shena's father from Dubai. She knew no better life than hers. Her past had been painful, her present seemed even more so. She had never known peace and had always lived in abject poverty.

Her case represented poverty, a robbed childhood, illness, deprivation and suffering in a war-torn country where health care is inaccessible for patients like Shena. She touched our hearts by sharing candidly stories of her life back home in Khost, her family, the two cows and little goats she used to play with, the father whom she longed to be with but who could rarely afford to come home. The truth came out of this little girl rather than from her too-proud grandfather. Hers were pertinent and authentic stories. There was also a side of her which was enduring the inhumanity this young girl had experienced as a result of lack of health care.

In time, Shena's health deteriorated and she suffered symptoms of extreme tiredness, shortness of breath, swelling in the ankles, feet, legs and abdomen and a build-up of blood and fluid in the lungs. Since health care services are almost non-existent in her home country, her family brought her back to Pakistan. The health expenses, transport and relocation placed an even heavier strain on the household. The totality of it hit them very hard and was devastating on this poor family. The lack of proper medicines compelled Shena's family to seek treatment elsewhere. Her father was able to obtain a loan for Shena and her grandfather to travel once more to Pakistan.

A simple surgical procedure, of which surgeons in Pakistan are adept, could save her life. The abnormal channel in her heart could be closed at a cost of less than US \$200. It is here that Heartfile intervened to support this procedure and Shena's life was saved.

The reach of Heartfile extended beyond borders to such a poor, young patient as Shena, who was saved by this surgery and given a chance to live a normal life. This is not likely to be the last battle she will fight in her poverty-stricken life. However, she has fought the ailment and not lost the spark in her eyes. Even in poverty, she was vibrant and continued to reflect real and great beauty and innocence.

We have learnt so much from this encounter with her. First and foremost, she has conveyed a personal experience and shown unique courage during this experience. Additionally, she is an enduring reminder of the inhumanity of poverty and its attendant lack of health care.

For over thirty years Afghanistan's children have lived in the midst of adult wars. Shena was left in a country which served her poorly. War has compounded the challenge for children like Shena. Afghan children have had to fight harder to survive than most others in the world.

This case acutely captured poverty, illness and deprivation. Hundreds of children in Afghanistan continue to lose their lives every year to complications arising from congenital heart defects. The absence of medical infrastructure and capacity for early detection means very few cases are cured. Only a very few who can afford the cost of transport, surgery and lodging will travel to Pakistan to seek treatment. Shena was among those very few and is perhaps now able to live a healthy life in her home town of Khost. Her story is a vivid narrative of a child, her health and her future survival.

Elderly Destitute Patients



There are several senior citizens, who are being grouped separately. A huge population of old people are left to fend for themselves. There is less availability of care givers when older people fall ill. Health services are ill-equipped to meet the needs of older sick people. The old patient endures a long journey, a long wait and the treatment they often receive is oriented towards acute rather than chronic conditions.

INAYATULLAH – A HIP FRACTURE

Providing care for one's ageing parents is a normal life experience. Some need help with heavy chores, some become too frail to live alone. For children to provide care for their parents is 'the right thing' in South Asia. Traditionally, parents grow old in the home of their eldest son, surrounded by family members. The case was different for Inayatullah, a 70-year-old widower, who had seven children all living in the same village, Chowinda, near the Indo-Pakistan border. Inayatullah however, lived all alone.

He had lost his spouse years ago and had been forced to suffer years of solitude, an isolated and sad way of spending the later years of life. As he grew old, he said, he grew more vulnerable and lonely. There was a tremendous void in his life as he was without any care or emotional support from his adult children and their families.

One day, he fell off his bicycle and was injured. The fall might have been due to poor balance caused by weakened bones. Older people are at higher risk of hip fractures because the bones tend to weaken with age. This nasty fall had disastrous consequences for the old man. He was left unattended for a month and finally his daughter, who was living in the city, went to check on her father when she had not heard from him. He had been in constant pain, unable to move the joint and so he was unable to perform basic daily activities like walking or taking a bath. He had lived with this physical pain for a long time. The injury caused stiffness and reduced his mobility. His left hip and leg had become terribly painful.

The daughter rushed her father, after borrowing money to pay for an ambulance, to PIMS in Islamabad. The fall had caused a fracture to the hip and had severely limited his ability to lead an active and independent life. He had become disabled. The fear created by the fall also made him psychologically disabled. He was in extreme pain in the hip and leg area and the pain increased with any movement of the left leg. X-rays revealed a hip fracture. A hip fracture is a break in the upper part of the femur, usually caused by a fall. People around sixty-five and older are most prone to hip fracture.

A hip fracture is a major medical problem among older adults, leading to impaired balance, gait and loss of functional independence and mobility. The hip joint is a ball and socket consisting of the acetabulum (socket) and the femoral head (ball). The femoral neck connects the femoral head to the proximal portion of the femoral shaft and attaches to the intertrochanteric region. The term 'hip fracture' is applied to fractures in any of these locations. Disruption of the blood supply to the head and neck of the femur can impair fracture healing in these structures.

In this patient's case the fracture occurred along the head of the femur in the hip joint. Support was requested from Heartfile for an operation package that included placement of a dynamic hip screw plate for the fracture of the femur. Inayatullah met all the criteria for the request to be immediately supported. The procedure entailed the placement of compression screws across the fracture. The screw would be attached to a plate which would be secured with other screws. As the bones healed, the screw would keep the edges of the fracture pressed together, which would ensure that they grew together correctly. Gamma nails would be placed along the compression screws to prevent sliding and would give more stability to the joint as it healed. Inayatullah would have surgical repair but would it be followed by the required months of physical therapy, we wondered.

Before the accident he had been robbed by his eldest son of his life savings of Rs.100,000 and of his only buffalo that had brought him a meagre monthly income through the sale of milk in the village.

His daughter said: "My father was in acute pain for over a month. I felt helpless when I visited him, seeing him in that condition." Inayatullah stated that poverty, malnutrition and illness had been as disastrous to his spirit as the familial rejection and loneliness. He had been subjected to both extremes. He had been isolated and rejected by his children and society. He said that during his illness, he had expected they would look after him. The phenomenon of the isolated elderly parent is becoming common across all levels of society as extended family structures are eroding. South Asia is becoming a tougher place to be old. Filial responsibility has become secondary to the main pursuit of self-advancement. There is additionally, a decline in respect for the elderly. The support

structure that would have provided an extended family network was not there for Inayatullah.

He was suffering from a health shock of severe magnitude combined with abandonment by his family. This had led to his daughter's forced debt to help her father, which had cast her into a debt trap and into her own chronic poverty. She opted for the treatment of her father and faced alone the catastrophic burden of his health care expenses. She was consequently in danger of becoming more impoverished. She was resilient and ready to face the consequences of poverty but was also ready to challenge the cruelty of the other siblings. The issues highlighted were not only poverty but old age, the changing culture of caring for elders, the vulnerability to falls and fractures among old people and the strength, caring and nurturing qualities of women.

REHMAT NOR - CAREGIVER TO THREE ORPHANS

Rehmat Nor had carried a tremendous burden for one so old. Here we have an elderly caregiver of eighty-one who had three orphans aged six, eight and ten years as dependents. The future of the entire family unit was as bleak as could be imagined. She was now left with total disability, had no one to help her, had immense fears about what lay ahead for her with no hope after two accidents disabled her. Life had never been easy for her.

A year ago, Rehmat Nor of Rhazial, a little village near Chakwal, slipped and sustained a leg fracture. She underwent surgery at Benazir Bhutto Hospital and a rod was placed in the leg. She became weak and less active but could manage her daily routine. She had another nastier fall later and was rushed to the local dispensary where the X-ray revealed a fracture of the hip bone. She was taken to the hospital three days later.

She was in constant pain, could not move the joint at all and thus performing basic activities was incredibly painful and difficult. She lived with increasing physical pain and very limited mobility. Her face and body had taken on a skeletal appearance. Her eyes had a vacant and lost look.

A hip replacement was planned. The hip replacement involved replacing the femoral head or ball of the thigh bone with a metal stem that fitted into the thigh bone. A metal socket and plastic liner are implanted into the pelvic bone (the hip bone) to replace the damaged socket. The prosthetic parts that mimic the natural design of the hip, fit together and function like a normal hip joint. They can be made of plastic, metal or ceramic. They may be cemented into place or coated with a biological material that induces the bone to grow into it. Recovery is slow but once recovered the patient can move without pain. Rehmat's survey was supported by Heartfile.

Rehmat was the caregiver to three children of her daughter and son-in-law who both passed away in an accident. This placed an enormous burden on an elderly grandmother. She had

to provide care within the context of her decreased economic means and serious personal health concerns, in addition to the normal challenges she was facing in extreme old age. This effort had to be made under extreme conditions of poverty and lack of any outside financial, physical or emotional support. With her advancing age, her health became progressively worse. She was socially isolated, depressed and anxious. The constant anxiety was caused by her worries about the future well-being of the orphans. In addition, the totality of the serious challenges that she had taken on had exacerbated her health and well-being.

The accident totally incapacitated her. Her family had fallen to the level of the poorest of the poor, with very limited income and insecure food supply. She was discriminated against within her society and was denied access to basic social and health services. Was the accident a result of the carer's irresponsibility? She was highly distressed, dishevelled and confused. She was fearful of being unable to continue her important role. She stated: "I am so afraid of what the future has in store for these babies. If I were to die and leave them, who would look after them?"

She had always been an independent woman who fulfilled her responsibilities and faced a challenge with courage. She was fully aware of the increasing disability ahead of her and she lived with immense anxiety. The high cost of treatment was one of her greatest worries as she was already in debt because of earlier surgery for the broken leg. Rehmat had been thrust into the role of primary carer for the orphans. She took on the responsibilities of parenting a second time and she said that it was an uphill challenge.

The culture of caring still dominates in Pakistan – the grandmother caring for the orphans and the children in time caring for the elderly woman. In this family the resources were severely limited, with no monetary input. A broader culture and outlook must be persuaded to improve the comfort and longevity of carers in such difficult cases, for the security and protection of both young and old. Such traditions and practices act as a stabiliser and a societal safety net.

This was a tale of illness and disability that had brought a family to the brink of despair in the absence of support.

AFSAR JAN – AN ELDERLY LADY WITH ORTHOPAEDIC PROBLEMS

Afsar Jan, a 75-year-old widow with grey hair, clad all in white, lay in distress and acute pain on a hospital bed. She hailed from a small village near Bagh in Azad Jammu and Kashmir, a region which was severely affected during the 2005 earthquake. Thus, Afsar and the family had already been victims of a brutal natural calamity. They were already poor and now were dealing with numerous issues, old and new, on multiple fronts.

Jan had one day suddenly slipped and sustained a right femur fracture. She complained of hip pain and was unable to walk. The affected leg appeared to have internally rotated and even passive motion was painful. X-rays revealed a minimal right femur neck fracture which would be best treated by insertion of a dynamic hip screw. Following successful surgery, it was hoped that she would be able to move normally and to place full weight on the affected leg.

The family could not bear the financial costs of the surgery and so Heartfile intervened at a crucial time, when the patient and her family so desperately needed support. Heartfile provided full assistance for the procedure as well as for her post-operative needs. This well-timed gesture indeed changed the course of Jan's deteriorating life and relieved a poor patient and family from a potentially disastrous situation.

Jan had reported a feeling of 'giving way' before falling. She was rushed to the local dispensary, taken later to Bagh Government Hospital, then referred to Rawalakot and finally she was brought to Benazir Bhutto Hospital in Rawalpindi. She roamed from hospital to hospital for a month during which nothing was done to determine the extent of her injury. She underwent the surgical procedure but we do not know how she is doing now.

There were many questions which arose after her surgery. After the procedure, would she be ambulatory with assistance from a cane? Would she be able to regain, after rehabilitation, a full range of mobility? The recovery ahead no doubt would be a long

one. She could possibly be left bed-ridden and suffering the life-changing trauma of not being able to walk again, or be greatly disabled with reduced mobility which would bring an increasing degree of dependence. Would she require long term nursing care? Would she still have ongoing chronic and severe pain? Would her fall lead to an early death? Studies have shown that in women aged 70-79, a hip fracture doubles the risk of their dying within a year. This might be a wake-up call for Afsar Jan. The first-year post operation, as she moved into her 76th birthday, would very likely be a critical time for her.

An interesting feature of Jan's home life was the role accepted by her daughter-in-law, an amazing woman on whom she depended entirely. She headed a household of eight and was the only wage-earning family member. She was a skilled lady who worked as a midwife in a local government hospital. In spite of suffering from a heart condition, she was the primary provider to her unemployed husband, Jan's son, who had cardiac problems, to their two deaf and dumb children, to another child with weakening eyesight, to her disabled mother-in-law and to two other healthy children. This lady paid an incredibly heavy price and carried a huge burden but her resilience and courage to bear her responsibilities with good grace surpassed all limits and credibility.

Persistence of abject poverty and ill-health did not stop Jan's courageous and determined daughter-in-law from fighting back while bearing the responsibility for her family's income, health, nutrition and education. She played the role of the matriarch to a large extended family. The daughter-in-law silently bore the cumulative burden of caregiver, provider, mother, wife and daughter.

She considered her primary duty as a daughter-in-law was to serve and honour her spouse's mother. She seemed to have learned this from her mother-in-law, who may have been in her early days a powerful woman but now at this stage had become powerless. The patient, who had been a devoted mother in her day, had not been forgotten by her daughter-in-law who still held her close as a revered mother. All of this strength was reflected in this case. Furthermore, the socio-cultural norms and family traditions of support and care were being clearly revealed in this narrative so there was hope for Afsar Jan's gradual recovery.

The family would probably continue to suffer from unrelenting poverty and persistent health problems; the struggle for daily livelihood would continue. If left untreated, Afsar Jan's illness would have increased immensely. Therefore, we are privileged to have played a small part in alleviating such suffering.

Patients in Bonded Labour



The last category of stories includes accounts of Patients in Bonded Labour—individuals who are generally invisible. Bonded labour workers are subject to health hazards which weaken their immune systems. They are victims of a modern form of slavery, tricked into enforced labour from which families cannot escape and free themselves from their bondage. Most of them experience lifelong poverty and ill-health.

AYESHA - BONDED LABOR

Ayesha was a ten-year-old female patient from a small mountainous village of Shangla, in the Swat district. Too weak to walk, she was carried along narrow tracks to the nearest road. There she caught the bus down to Saidu Sharif for the Government Hospital. She went to the doctor with a history of cough, fever and weight loss and with haemoptysis (blood in the sputum) on and off for the past eight months. The haemoptysis bouts had increased over the past one month.

Ayesha was admitted to the emergency department of the hospital. The doctors diagnosed serious pneumonia, with fluid in the lungs. During her hospitalization in Swat, there was no improvement. Thus, she was referred to Lady Reading Hospital in Peshawar for specialist attention. The thoracic ward of LRH never turns away a child with a treatable condition. There, chest X-rays revealed an infected hydatid cyst in the right, lower quarter of the lung. A hydatid disease is a parasitic infestation which is potentially fatal. The diagnosis was further confirmed by her family's history of exposure to pet dogs and cattle. The hydatid tapeworms commonly infect dogs. The child must have come into contact with infected dog faeces and contracted hydatid disease. She was scheduled for surgery, which was supported by Heartfile.

The family of eleven earned Rs. 4000 per month as bonded laborers and could only afford the cost of some drugs, so the cost of transport, relocation, maintenance and the support of attendants in Peshawar was met by a loan from their landlord. Knowledge about such constraints led Heartfile to subsequently open a channel of assistance for patients' families that cover the cost of transportation and sustenance during treatment; this channel has helped thousands of patients.

Ayesha's ancestors had been bonded when they incurred high interest loans from the local landlord. Thus, they were compelled, generation after generation, to work at very low wages to pay off the debt. They continued to be among the poorest and most vulnerable in their village. The father said that during harvest time he worked up to fourteen hours a day for the landlord in return for Rs.100. He added that he had no other choice as he was trapped

in debt. Due to the lack of options, his family had for generations been forced to work for the local “Khan” and had gradually ended up in perpetual bondage.

Ayesha’s parents were well below the poverty line and they feared that their children too would never escape their bondage. Ayesha’s mother said that she was born poor and feared she would die poor without being able to ensure a better life for her children. Nevertheless, she lived for them and now, with Ayesha sick, she felt the life she had worked so hard to rebuild had collapsed. She worked for over twelve hours attending to the family of the landlord whereas her own family would continue to be the poorest in a neighbourhood of very poor people, a charity case even for those who had nothing.

The practice of bonded labour continues unabated in Pakistan because of a failure to implement laws already in existence. Bonded labour must be addressed, starting from the premise that the poorest households’ lack of access to appropriate financial services is one of the main causes of bonded labour. Preventive efforts must recognize the essential dimensions of the bonded labour problem. The persistence of bondage is a result of weak enforcement of labour laws and the laws of the land. The violation of the fundamental human rights of workers such as Ayesha’s parents will be perpetuated if the situation stays as it is. Such family units continue to suffer deprivation of both their freedom and their dignity. Aspects of socio-economic inequality and the violation of a right to health care are deeply entrenched when a family is in bondage to a wealthy and powerful landlord. With such a strong submission of the poor in place, it remains a challenge to ensure the quality of life of the poor in a so-called democratic country which does not implement the policies protecting the rights of the marginalized poor.

Ayesha will be discharged after the procedure. She will return to her village. It remains uncertain whether the family will bring her back for a follow up X-ray after three months, to ascertain whether she has been cured completely and to counter any risk of the condition developing again. Presently, the cost for the family has been very high and they cannot afford to envision any more spending in the next three months. If there is need for further treatment, Heartfile will surely step in.

MAHJABEEN – A PATIENT OF CHRONIC LIVER DISEASE

Fifty-nine-year-old Mahjabeen lay on her hospital bed in a foetal position, shaking with pain, pale and extremely weak. She looked like death itself. Her family was told that she would not survive long on account of advanced chronic liver disease. They were told that she could die in the hospital or go home to die as her prognosis was totally negative. What a cruel statement, devoid of any compassion. The family was devastated but insisted that she should be attended to. The doctors agreed to administer treatment, if only to make her a little comfortable.

Mahjabeen suffered from Hepatitis C which was left untreated for 6 years and later developed into chronic liver disease. No major symptom was detected during the early stages of the ailment but gradually she started losing weight and developed symptoms of fatigue and jaundice. She was only taken to the local government hospital after she vomited blood profusely.

She was immediately referred to Lady Reading Hospital in Peshawar, where she was diagnosed with gastro-oesophageal varices. Oesophageal variceal haemorrhage is a devastating complication of cirrhosis of the liver that carries the risk of mortality. Varices are extremely dilated veins in the lower third of the Oesophagus. They are most often a consequence of portal hypertension; in individuals suffering from cirrhosis these varices have a strong tendency to bleed. A package of varices band ligators was requested from Heartfile to manage the acute bleeding and to minimize the risk of recurrence. Often patients like Mahjabeen are left to bleed as families and hospitals do not consider it a good investment to spend on a patient who is dying anyway. Heartfile makes it a point to support such patients during their last days and to offer palliative care, so that their dignity is preserved. There is a group of gastroenterologists regularly seeking help from Heartfile for varices band ligators to help end-stage patients from bleeding to death.

This treatment involves the strangulation of the varices by applying rubber bands. Band ligators are attached to the end of an endoscope. Intubation is performed as with standard

endoscopy and once a varix is found, suction is applied and a band is deployed. As banding acts more superficially, recurrence of bleeding varices is still common and repeated ligation is often required.

Mahjabeen came from a small village in the mountainous region of Pir Baba in the Buner district of Khyber Pakhtunkhwa, a scenic area of great beauty with gushing streams and beautiful lakes. Access to any major town is by a difficult five-mile walk, or via a road traversable only by four-wheel drive vehicles. The family had to hire a jeep to transport the patient.

This area is known best for its forests which are being gradually depleted by timber mafias. The locals are also dependent on this forest to meet their timber, fuel and fodder requirements. A few locals and non-locals started illegal timber businesses causing forest depletion uncontrolled by the government authorities. Mahjabeen's family has been bonded to the forest mafias for generations. Her whole family has been engaged in wood-cutting. Her sons started working at the tender age of eight, as have the women of the house. The timber mafias exercise a tremendous amount of influence in the area and the trees are being ruthlessly harvested and sold on the black market while the authorities responsible look the other way.

Both the Forest Department personnel and the police operate in collusion with the timber mafias, striking bargains with them. The wood-cutters, including the family of Mahjabeen, worked at their own risk. Their lives and labour had been used as collateral against loans whose interest kept accumulating. Mahjabeen's spouse, who was also present, stated that his whole family had been forced into the condition of slavery by the mafia. They were trapped in debt bondage and forced to repay unpayable loans. He added that they were compelled to work for long hours for pitiful wages, of which half was retained by the landlord as payment towards the loans. He complained that the loans might take a generation or more to pay off and that they would die in this forced bondage. Each working member of the family spent twelve hours a day, every day of the week, cutting wood for a pittance.

Being poor, Mahjabeen's family could not afford even to transport her to the nearest local hospital and so she was neglected. Her health did not seem to be a matter of concern to this family of nineteen. Mahjabeen's spouse mentioned that she had always suffered in silence. Poverty had exerted a powerful influence on Mahjabeen's health since it was associated with the complete neglect of a woman's health and lack of access to any health care, complicated further by long hours of physically demanding labour. Numerous issues had been involved with this case – poverty, gender inequality, bondage, lack of health services and the acceptance that cure is not possible for a chronic disease. All these conditions were exacerbated by and directly resulted from the horrendous ongoing depletion of natural resources and the corruption of local authorities.

ZARWARI – A WIDOW

Widowhood represents social death for a poor, sick woman in Pakistan. Children are withdrawn from school, deprived of their right to education and exposed to exploitation as child labour. Stigmatization and constant discrimination add to the woman's miseries. Ill-health combined with poverty and widowhood are a devastating shock both to the widow and her children. Sickness, poverty and widowhood are visible through a woman's hunger, pain, exhaustion, isolation and powerlessness.

Zarwari, a fifty-year-old woman, came with worsening right-side chest pain, cough and non-productive sputum. She had a history of lost appetite and lost weight. The X-ray and CT scan demonstrated a well-demarcated mass in the region of the right middle lobe of her lung.

The treatment plan was an open pleural biopsy, for which support was requested from Heartfile. An open pleural biopsy is a procedure to remove and examine the tissue that lines the inside of the chest. This tissue is called pleura. The procedure is done under general anaesthesia. In Zarwari's case the procedure was carried out to examine the pleural mass.

Zarwari delayed treatment (and therefore payment) for as long as possible, until she became critically ill. She was a single mother, the head of a household of seven dependents. They lived as bonded labourers on the lands of the local landlord in a distant village near Mardan. The lives of the whole family were mortgaged to the landlord. Poverty, limited skills and debt trapped the family in low-paid, wage-bonded labour. The cost of this labour would be paid by them over a lifetime through loss of health.

She said that life had been an uphill struggle. "My children have been compelled to enter the workforce at a young age to help meet household and treatment costs. The necessity of removing children from school at a young age has meant my poverty has been transmitted to them. My own journey through years of pain, anguish and poverty will come to an end which is death."

She said that her children were affected both emotionally and economically when she became both a widow and seriously ill. She had been left destitute, totally dependent on charity and her children's labour. Poor nutrition and inadequate shelter, combined with a lack of health care, had impacted the family's physical and mental wellbeing. Her ill-health had affected her deeply personally. Her ailment could be viewed as an inherent part of being poor.

Zarwari's hands were rough, and her feet worn hard by hours spent working on the land. While sitting on her hospital bed narrating her hardships, the sad expression on her lined face was unmistakable. She added that she had no choice but to work. The hardest and most painful decision the family had to make was to choose treatment either for her or for her sixteen-year-old daughter, who also had a chronic chest ailment: they could not afford the treatment for both. The family was being forced to go deeper into debt with the medical expenses and relocation for treatment. They had so far made sizeable out-of-pocket payments and had to borrow money to pay for them.

The health system in Pakistan has failed to protect poor families from financial risks of seeking health care and hence the importance of the work of Heartfile Health Financing. Poverty, ill-health and weariness have been lifelong companions for Zarwari. In sickness she felt that she was a burden on her family. The cost of treatment pushed her even further into poverty. Even while foregoing treatment for her child, she had to choose between food for her family and spending money on her own treatment. This was a decision taken by her sons: they needed their mother. Ill-health, no escape from dawn to dusk work, poverty and hunger all added up to a bleak future. She would suffer emotional, physical and financial trauma if the biopsy revealed serious problems. The family would then suffer disastrous depths of poverty and debt as her health worsened.

Conclusion

Situations of social marginalization, poverty, lack of economic opportunities, denial of the right to health care, are the causes and core of all the miseries of poor patients. The levels of marginalization and poverty defy belief. The poverty, so apparent during the foregoing assessments, is perversely invisible to us all. We do not want to see it; we do not want to know it. This poverty makes the situation of every patient assessed more precarious.

The pressing need is to set up a fund and a system to support these very poor but deserving patients – a fund and system to save lives, a means to counter the disability and destitution caused by medical treatment which is not affordable.

This support from Heartfile Health Financing (HHF), be it through assistance for corrective surgery or a package for diagnostic tests for a cancer patient, has been lifesaving for poor patients who were thereby ensured access to badly needed help.

Over the past several years, Heartfile Health Financing has reached out to thousands of patients; dignity has been restored, hope has been revived, stigma has been overcome and foremost, the process of healing has been initiated. Patients, through their pain, have asserted their needs, thoughts, limitations, feelings and emotions and taken control of their lives in the midst of terrible suffering. HHF was a step forward for many poor patients looking for an alternate method that challenges fundamental inequality.

Each case leaves an impression on our minds and will keep on haunting us. The moment when we realized our power to affect change in the life of a patient has been a powerful one. Witnessing stories of these patients touched something in our own lives. Personal stories become mirrors. Looking into them, we are inspired to examine our own strengths and abilities to affect our world. We can have the power to change the lives of people who do not have a vested interest in the status quo. Women and men for example have the power, if they can use it, to work from their positions of vulnerability to effect change, sometimes,

before it can be noticed. This power is the necessary starting point of all of Heartfile's work and aspirations.

The parallels in the issues of the patients and their experiences are obvious; there is a universality to each patient's experience, to their pain, to their struggle and towards the spirit of overcoming suffering. More and more we are convinced of the common ground on which all the patients are struggling and the common goals of healing towards which all the patients are striving. The common ground obviously is poverty, deprivation and the denial of the basic right to life.

Heartfile Health Financing is a powerful model of staff working together. We see how we can be inspired and supported by each other, how we can bring change in the lives of vulnerable patients and actualize the significant impact their bondage has on each one of us.

It feels good being part of this initiative and being associated with HHF. We have often felt that Heartfile has charged our batteries and one goes on with the struggle, building one's strength to carry on the battle for change as the State turns its back on all these urgent issues which should be addressed. The State has failed in its role as provider of basic services such as health care and consequently, poor households have been left with the dilemma of ruinous debt or foregoing treatment.

As we reflect on the stories, we are struck by the courage, faith, hope and sheer endurance of each patient and loved one animating each narrative. How their words carry the power to bolster resolve and dispel doubt!

All at HHF are fighters for change in health care, people with ideas and ideals, courageous individuals undaunted by challenge. Dr. Nishtar has shown the courage to dream, the passion to believe and the strength to act. This book speaks of her dedication, inspiration and energy, her efforts are marked by the intensity of her compassion, to alleviate the pain of poor patients. The book demonstrates the breadth of her vision and the depth of her compassion.

In depicting these stories an effort has been made to project a profound sense of humility and humanity. Through the stories we are taught about the importance of dignity and respect for humankind, especially those who are in pain and cannot alleviate it alone. It is here that Heartfile seeks to make a difference.

This, hopefully, will inspire and motivate others. HHF has quietly and consistently touched the lives of many. Effort has been made to draw attention to the plight of those in less fortunate circumstances, those of the poor whose suffering we often ignore.

In conversations the pain of patients suddenly flared up like a flame. Often, unlike the devastation of fire, this flame has had the power to ignite and nourish our souls with hope and the need to do more for our patients. We seem to connect with each patient whose courage fills us with the confidence of being able to bring about change by responding to their plight.

The patients have taught us resilience and courage. They have known suffering and strife, experienced loss, they have struggled to find their way out of the depths of despair. Each story is intended not only to be an explanation of the patient's violated right to health care and their poverty but is also a salute to each one as an outstanding representative of the human race. All have had to look at life with despair but often with hope too. The heart-breaking pain of these patients and their strength in bearing it, speaks volumes for their strength and bodes well for the survival of a vulnerable group who have been deprived of their right to health care.

We hope that all of us will pool our efforts to effect change in a deficient public health care system and that we become a powerful force for the benefit of suffering patients who cannot afford medical care.

Recollections of the patients inspired me to write this collection of stories. This piece of writing reflects the plight of poor patients and in telling of the seriousness of the issues, it is for the reader to learn from, share and deal with these stories. With this modest collection we wish to pay homage not only to the patients depicted but also to Dr. Sania Nishtar and

the many people at Heartfile who reach out every day with large and small gestures of goodwill and courage in supporting their patients.

We hope this book will allow readers to see something of these lives and feel the strength of these hearts for a brief moment and be informed by them and inspired by their struggle as we have been. With this book we hope to pioneer a new way of caring for all our people, to open door after door to a just and fair health care system. It will certainly be a mighty step across the national stage of Pakistan.

Is health care viewed as a public good or must it defer to political processes, allowing elected representatives to determine the form the health care system takes? The discourse on health care as a right is ongoing.

Regardless of how the issue of health care impoverishment is approached, it is misleading to speak of a 'crisis' in isolation. Rather it must be viewed as an integral part of bad governance. It is a crisis of the policy-makers' making, of the implementers, of how the whole health care system is perceived, leading to the denial of a basic right. It does not present itself as an economic and social crisis for the rich. The patients who cannot afford medical treatment present a major strain on the system. It is for the State to overhaul the system in terms of budgetary constraints, hospitals, their management, financial and human resources and foremost, a humane and compassionate attitude in all medical staff and practitioners.

Why did these experiences have to be documented? It is the result of HHF's awareness of the gaps in the health care system and the poverty of patients in Pakistan which has gone unnoticed. The array of illnesses of poor patients was shocking and we felt the need to prevent these lives of suffering from being ignored and forgotten. Sharing these stories may open our eyes to the reality of those who are in agony and deprived of treatment. These stories have been captured here for others to regard and wonder at and also to be reminded that these patients are human beings like us.

Providing health care assistance to each patient referred is the most important aspect of HHF's mission, and HHF will be judged as an organization by the kind of service and

assistance it gives to the poorest of the poor and to the most vulnerable groups in our society. Heartfile has set an example for all involved in health care with its ground-breaking program, Heartfile Health Financing. It is an eye-opener for NGOs of every kind. Dr. Sania Nishtar is a friend to humanity in general, a human treasure, a truly caring and compassionate soul. Her dedication is like a ray of hope amidst great chaos. Hers is a life completely devoted to mankind and as such is totally meaningful.

When the reader finishes reading this book, they too may find that their world is not quite the same.