

Letter from Ganiyari

THE RESPONSIBILITIES OF PUBLIC HEALTH SYSTEMS

Eleven-year-old Seema Gond was brought in dead to our casualty in mid-September 2015. She looked excessively pale and jaundiced and had prominent maxillae. Her hugely enlarged spleen was easily palpated. On direct questioning, her mother said Seema often had pain in her knees and elbows.

Based on central India's epidemiological patterns, Seema's illness seemed to fit into sickle cell disease—a treatable illness in most patients. With appropriate preventive and treatment measures, an almost normal life span with an excellent quality of life can be assured for majority of patients with sickle cell disease.

A postmortem blood sample confirmed that her haemoglobin level was 1 g/dl; her peripheral smear showed marked haemolysis, a reticulocyte count of 20% and abundant fixed sickle cells.

While compiling her death summary, our health programme's electronic medical record system showed that Seema had visited our clinic a year and a half ago. She had been examined by a paediatrician who suspected sickle cell disease and sent her blood sample for haemoglobin electrophoresis. Since this test is done weekly, Seema was asked to follow-up in 7 days. That test report confirmed that she had homozygous sickle cell disease.

Even though Seema remained sick, she did not make her follow-up visits. Their home was about 35 kilometres north of the hospital. On the day of her death, her distraught mother told us that Seema's father was heavily dependent on alcohol and his struggle with addiction prevented them from visiting the clinic again.

It rankled us that our records knew for at least 17 months that living not far from our hospital was a young girl who had sickle cell disease. But hospitals (including ours) function on the premise that care is to be provided when sought; our system is not equipped to actively review the results of diagnostic investigations that become available after the patient has gone home. No mechanism exists to inform people and encourage them to come back and seek appropriate care.

Perhaps Seema's parents would have sought care if they knew that she had a treatable disease. Her haemoglobin level may have never dropped from 8 g/dl to 1 g/dl. Seema may have survived.

Seema's death led us to ask if such events are common in our clinics. How many treatable diseases after diagnoses lay trapped in our electronic and paper files? We searched our electronic records (for a few select investigations whose results are not immediate) over a 6-month period from April to September 2015. We looked for positive results of tests that would certainly modify clinical management: haemoglobin electrophoresis, HIV serology, tuberculosis sputum culture or cartridge-based nucleic acid amplification test (CBNAAT) and thyroid function tests (Table I).

Among 199 positive results, 27 (14%) patients did not come for follow-up. Half of missed diagnoses (15/27) were individuals

with SS (inherited Hb S gene from both parents) sickle cell disease (like Seema). Even though rather late, we are hastily trying to trace them and encourage them to seek further care. For tissue samples that were sent out for histopathological examination, the majority of which would be for a possible malignancy, the percentage of defaulters was similar. Are we remiss in our responsibility?

Should hospitals in India *be required* to inform patients about results that are potentially treatment changing? The National Accreditation Board for Hospital and Healthcare Providers¹ mandates that clinical laboratories should communicate critical laboratory results to ordering physicians but is silent about the responsibility of the hospital or physician to inform the patient.

How many hospitals in the country consider it their responsibility to inform patients about results that are potentially treatment changing? I suspect very few. This would happen for histopathology samples, microbiology cultures, expensive biochemical and hormonal tests where for exploiting the economy of scale, testing is often centralized far away from sites of care, for tests such as ELISA and electrophoresis where laboratories usually perform these tests in a periodic non-urgent frequency. There is something to say for point-of-care tests for all these conditions.

This raises a question. Who is responsible to ensure completeness of healthcare-seeking—the healthcare system or the patient? The spectrum of possibilities ranges from a publicly funded universal health coverage with active community outreach programme to a private laissez-faire system where people seek care according to their choice and economic status. In the latter, patients are responsible for ensuring their own healthcare. One can argue that the family should have responsibility for patient care like they have it for other needs. However, it is important to not confuse responsibility with ability. Paul Farmer said that 'non-compliance is usually a matter of ability rather than agency. Throughout the world those who are least likely to comply with treatment are those who are least able to comply'.²

A second key question is: What is the ethical responsibility of a hospital-based system? Should hospitals only make good internal systems so that they provide effective, humane and low-cost care to all those who actively seek care with them, or do they have a responsibility for all those who have sought care even once? Do hospitals have a responsibility to ensure that patients know about their diagnoses? And further to ensure care? Do they have a responsibility to reach out to them? Can they define a geographical area in which they will ensure to inform and/or provide continued care to patients?

The ethical standard for community health programmes or epidemiology researchers is that screening for a condition mandates one to be able to provide care for each detected case. When an epidemiologist screens for cancer of the cervix, or tuberculosis or

TABLE I. Missed diagnostic opportunities (Jan Swasthya Sahyog, April to September 2015)

Laboratory test	Haemoglobin electrophoresis	HIV ELISA	Sputum culture	Thyroid function tests	Total
Total	65	18	96	20	199
Patients are on treatment/informed/ started on treatment/died	50	14	92	16	172
Missed information/treatment	15 (23.1%)	4 (22.2%)	4 (4.2%)	4 (20%)	27 (14%)

neonatal hypothyroidism, it is assumed that she will provide care for those detected to be sick. In the 55 villages in our community programme, we track all major illnesses for which people seek healthcare. When individuals fail to follow-up, we contact them and encourage them to continue care.

For a hospital-based system, how far does the responsibility extend? Does the responsibility end when the patient leaves its premises or does it continue until the diagnosis is made and an evidence-based treatment plan is prescribed; or does it extend to factor in the unique social circumstances and values to restore health and dignity; or does it extend even beyond that?

We believe that the hospital is an important 'citizen' in the community. It bears witness to ailments of the society and has an ethical obligation to make that full diagnosis and prescribe treatment by advocating for systemic changes. Seema's life course would have been different if her father's problem of alcohol abuse had been addressed.

These are lofty goals. Yet a journey of a thousand miles begins with one step. For us, that first step is to build a workflow using our electronic medical records to ensure that patients are informed about critical reports and advised next steps, even if they miss the follow-up appointment. This will be extra work with its own demands but one hopes for long-term improvements by avoiding delay in care for treatable conditions such as sickle cell disease. A disease that took Seema's life.

REFERENCES

- 1 *Standards for Accreditation of Clinics Practicing Modern System of Medicine (Allopathy)*. New Delhi: National Accreditation Board for Hospital and Healthcare Providers; 2011, chapter AAC 7e, 10–12.
- 2 Farmer P. Immodest claims of causality. In: Farmer P. *Infections and inequalities—The modern plagues*. Berkeley: University of California Press; 1999:255.

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Letter from Bristol

ENGAGING FATHERS IN THE TREATMENT AND PREVENTION OF POSTNATAL DEPRESSION

Depression during the perinatal period is common. Between 11% and 15% of mothers experience clinical depression during pregnancy and in the 3 months after giving birth.¹ Depression during pregnancy is strongly associated with postnatal depression, which is, in turn, a strong risk factor for future chronic depression.¹ Mental health problems in fathers are also common during the perinatal period, affecting almost 1 in 10 fathers in the period between the first trimester and 1 year postnatal.² In addition, maternal depression is strongly linked to paternal depression and partners of depressed mothers are twice as likely to develop depression.²

It is well known that maternal depression during the perinatal period can have adverse consequences for the health and well-being of the mother, her children and her family if it goes unrecognized and untreated.¹ However, the health and development of children is also influenced by the mental health of fathers.³ When fathers also become depressed, the combined effect of depression in both parents increases the risk for a range of negative outcomes in children.³ On the other hand, involvement of a non-depressed father may be particularly important for children in families in which the mother is depressed. Involved fathers may buffer against the adverse effects of maternal depression by providing the child with a sensitive and responsive environment necessary for healthy development. There is a need for greater understanding of the mechanisms by which fathers protect their children from the adverse impact of maternal depression. These insights will contribute towards development of early interventions aimed at improving postnatal mental health in parents and children.

Lack of partner support during pregnancy and in the postnatal period is a strong risk factor for postnatal depression.² In contrast,

women whose partners are emotionally and practically supportive during pregnancy and after the birth of the child report improved postnatal physical and mental health.⁴ Partners are also instrumental in supporting mothers from depression and in encouraging them to seek help.⁴ Half of postnatal depression cases in women go undiagnosed and women often report reluctance to seek help because their partners are dismissive of their symptoms.⁵ It is therefore important to educate men about depression and how it may affect their partner during pregnancy. This may improve the early detection of symptoms, encourage help-seeking and facilitate preventive interventions to improve mental health in both parents.

Maternal depression does not happen in isolation and is likely to affect the whole family unit. This includes fathers who are also adjusting to fatherhood as well as trying to cope with the distress of their partners. Qualitative studies suggest that fathers experience fear, confusion, concern for their partners and a sense of hopelessness when it comes to helping their depressed partners.⁶ Moreover, fathers primarily turn to their partners for emotional support, particularly after the birth of the child. When the mother is depressed, she may be less supportive of her partner which may further contribute to his stress. The long-term adverse effects of parental depression call for interventions that acknowledge the role of fathers in supporting mothers through depression. Such interventions should also be sensitive to the emotional needs of fathers. So far, only a small number of studies have included fathers into therapeutic efforts to prevent postnatal depression in mothers. None of these focused on depression in fathers.⁷

Because of frequent contact with the health services, pregnancy provides an ideal window of opportunity to address parental mental health. Antenatal efforts to prevent postnatal depression often focus on enhancing social support.⁸ Increasing emotional and practical support of partners has also been found effective in treating maternal postnatal depression.⁹ On the other hand, low