

Patient Pathways and Diagnostic Value in Sierra Leone

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Abstract

What is the value of a diagnostic test? Most obviously for primary healthcare settings, laboratory tests can inform clinical decision making about treatment and patient management. Their predominant value in this context is therefore medical. But what about when that healthcare setting is chronically under-resourced, healthcare workers (including laboratory workers) are underpaid, and government supply chains fail to deliver basic laboratory supplies? In this contribution to the Field Notes section, we describe a Community Health Centre (CHC) in Sierra Leone where such conditions have given rise to a quasi-private laboratory service within the public health facility. Through detailed ethnographic description of patients' diagnostic pathways through the facility, we examine and assess the impact on patient care when the medical and economic value of diagnostic tests diverge.

Keywords

Diagnostics, Sierra Leone, Global health, Value, Patient pathway.

Introduction

Known to the local population by the Krio name ‘Bottom Mango’ (denoting its position under the mango tree), the Community Health Centre (CHC) sits on the side of the main highway linking Freetown with Western Area and Sierra Leone’s four provinces. The health centre shares one fence with a US-sponsored private mission hospital. Another fence marks the boundary of a colourful private nursery and pre-school that serves the nurses, many of whom live in the area with their families. Next to the gate stand two big trees, beneath which people often gather to sit or stand in the shade when waiting for motorbikes to arrive and carry them home. Outside the gate, vendors sell foodstuffs, baby items, and second-hand clothes from metal tables. The vendors sometimes give credit to health workers from the health centre at the end of the day, as the health workers allow the vendors to store their stock in the hospital’s incinerator room (the incinerator doesn’t work).

Security staff open the large vehicle gate at 7 a.m. and close it at 6 p.m.; patients must use the small brown pedestrian gate alongside. To the left of the gate is a small shelter with a long bench and a single chair out front. This checkpoint operated as a screening area during the Ebola outbreak and now plays host to security guards and cleaners hiding from the heat of the day. There’s a tap that was used for hygiene purposes during Ebola screening, but it no longer works because of water shortages.

The CHC is staffed by 56 people, of whom 31 are salaried staff (also known as ‘pin-coded staff’ after the six-digit pin-codes used for personal identification) included on the government’s payroll. The other 25 unsalaried staff, commonly referred to as ‘volunteers’, are predominantly young women, of which the majority are working as state-enrolled community health nurses or maternal and child health aides in the maternity department. For four months in 2019, these staff members were joined by Fatmata Bah, a research assistant on the ERC-funded DiaDev project.¹ Fatmata carried out daily observations in the health centre’s consultation rooms, waiting halls, and laboratory, following the pathways that patients took through the health centre and focusing on how those pathways were structured by medical testing and diagnostic processes.

Laboratory medicine has long been a neglected component of national health system plans and global health investment in many low- and middle-income countries (Ondoa et al. 2017). In Sierra Leone, the 2014–2016 Ebola outbreak exposed significant gaps in the country’s laboratory system and prompted a wide range of international assistance in terms of laboratory support and emergency

1 See www.diadev.eu.

preparedness. Although these international investments significantly improved the nation's molecular diagnostic capacity to diagnose Ebola and other diseases considered threats to global health security, fewer investments were made to improve the capacity to diagnose common febrile illnesses, such as malaria and typhoid, in the country's clinical laboratories (Vernooij et al. 2020).

In this Field Notes contribution, we provide a thick description of the diagnostic infrastructure available at a government-managed CHC in Sierra Leone. In doing so, we aim to situate diagnostic work in the everyday relationships that characterise the social life of a peri-urban health facility, highlight the formal and informal work it takes to produce diagnostic results, and illustrate the impact that limitations in diagnostic infrastructure have on patient care (Chabrol 2018; Street 2014). In what follows, we trace the spatial practices and social interactions that occur along a health centre patient's diagnostic pathway. By engaging in 'thick description' of diagnostic pathways, we show that the value of diagnostic tests emerges under specific infrastructural, social, and economic circumstances rather than being a quality of the diagnostic product itself.

First stop: The waiting hall

From the main entrance, the route to the waiting hall leads up a narrow ramp (for the use of wheelchairs and stretchers) or steps (for those who can walk). In the waiting hall, patients and their relatives can buy medical forms (at the cost of 5,000 leones each, roughly 0.40 GBP) from one of seven nurses, who sit at two large tables. Forms secured, patients then wait on one of seven long benches to see a health worker. There are four rooms leading off the waiting hall: two for community health officer (CHO) consultations and two for treatment. Immunisations for children under five take place in the waiting hall and a deep freezer used to store vaccines and icepacks sits against the wall. There is also a cupboard housing equipment for under-five immunisations, including a weighing bowl and a height board.

Even with four large windows kept open to improve airflow, the hall is busy and stuffy, especially when immunisations are taking place. The hall can be a chaotic and confusing place for patients; it is not always clear, for example, which nurse medical forms should be purchased from. After they fill in the form, patients must wait for a nurse to photocopy it before they can see the CHO. When the hall is busy, there is often nowhere to sit, and patients who leave the hall for fresh air risk missing their names being called. If a patient complains about the long wait, often a nurse will respond by shouting at them and telling them to wait until they are called. Some patients leave the health centre after several hours of waiting, their names still uncalled.

Ordering a test

When a patient is called by a nurse, the next step in the diagnostic process is the ordering of tests, which takes place in the community health officer's (CHO's) office during the consultation. This is often an awkward and uncomfortable interaction for patients, who are rarely told what they are being tested for or why. We found that, while the CHO appreciated the diagnostic value of testing, testing prior to treatment was not always feasible, especially when patients did not have money to pay for both tests and treatment. When the CHO refrained from sending patients to the laboratory, the lab staff would complain he was withholding business from them (a point to which we will return later on).

Inside the CHO's office, there is an examination bed, which is not used for examinations; it is for the volunteer staff to sit on. Next to the bed there is a table with a bucket of water, hand soap, and a cup, which is used to take water from the bucket for handwashing because there is no running water. Also in the room is a non-functional freezer, a dustbin used for both medical and general waste, and some shelves bearing a tray of surgical instruments and other surgical items, including gauze, iodine, bandages, and plasters. A dustbin is labelled 'clean water' but is used for general waste. Two CHOs, one CHO-in-training, one community health assistant, and three nurses, all of whom are volunteers, work in this room and assist the CHO-in-charge by calling in patients, administering IV fluids, directing patients to the treatment room, and admitting patients for minor surgical procedures.

The patient enters the CHO's office when the CHO, having read their name on the medical form, calls them. The patient takes a seat at the table in front of the CHO's desk. The CHO asks patients about their symptoms and writes a short summary of their complaints on the medical form. The CHO does not conduct a physical examination and nor do they take vital signs; this is only done for visibly 'severely sick' patients. Sometimes, a patient will state their presumptive diagnosis: 'I have typhoid', for example. The CHO usually requests a minimum of three tests for any patient presenting with self-reported fever at the facility (malaria, haemoglobin, and HIV). More tests are added based on clinical presentation and/or medical history. In many cases, however, patients are prescribed the same rota of tests (malaria, haemoglobin, HIV, Widal for typhoid, urinalysis, and syphilis) regardless of symptoms. The CHO has a point-of-care blood glucose device in his office which is used by nurses to measure the blood glucose levels of diabetic patients, a privilege for which the patient pays 10,000 leones (0.70 GBP) directly to the CHO, who owns the diagnostic device and purchases the testing strips.

There is no privacy in the office; patients are often shy or intimidated and the CHO does not invite questions. The CHO writes the requested tests on the medical form

and asks the patient to go to the laboratory before prescribing medications. In some instances, when the CHO suspects the patient may be severely sick or not have enough money to pay for testing and medication, he requests money for medications and administers an IV drip or injection to treat the patient without first referring them for a test.

The laboratory

After tests are ordered, the patient needs to present the medical form to the health centre's laboratory. Fairly early during fieldwork, Fatmata found out (through building rapport with a laboratory technician whose relative was supplying diagnostics to the laboratory) that the diagnostic tests were of economic value to the laboratory staff. Whilst the laboratory is officially part of the government clinic and the laboratory workers each have a government salary pin-code, the lab rarely receives reagents or equipment from the government. Instead, the staff run the laboratory as a private business.

The lab building stands at the far end of the hospital compound—a 100-metre walk from the consultation office. A long corridor spanning the length of the building serves as a waiting hall for patients. A single crowded room with three windows houses all the laboratory services for general outpatients as well as occasional in-patients. A senior female lab technician presides over a jovial team of four lab technicians who work daily from 8.00 a.m. to 6 p.m. The phone number of one staff member, who resides in the health centre's compound, is listed on the door in case of a night-time emergency.

The lab has no water and no toilet for patients. Patients use the back of the laboratory storeroom when they are asked to complete a urinary test. The lab and health centre have 24-hours-a-day electricity provided by the grid, a system of solar panels, and a back-up generator, all of which are supported by the non-profit organisation AIDS Healthcare Foundation (AHF), which runs the HIV clinic at the compound. Available equipment includes a microscope, which was donated for tuberculosis control over twenty years prior; laboratory workers regularly clean it and change any faulty parts. A centrifuge is used to spin and separate blood, as when performing a Widal test to diagnose typhoid. A chest freezer, currently non-functional, is used to store items like gloves, tubes, and other lab materials. An air-conditioning unit—also non-functional—was donated by AHF. A hanging cupboard nailed to the wall is used to store empty boxes and reagents. Additionally, there is one incubator, used to store microscope slides, and another, donated by AHF, used to store empty test tubes. Because of the lack of a working refrigerator and air-conditioning unit, it is not possible to regulate room temperature, which is generally above 30 degrees Celsius, exceeding the temperature range

recommended for the storage of rapid diagnostic tests (RDTs) and laboratory reagents. The laboratory technician who lives at the compound therefore keeps the health centre's RDTs and laboratory reagents in his personal home freezer so as to preserve their quality.

To collect urine and stool samples, laboratory workers beg used medication bottles from their colleagues working in the treatment room. Some patients will buy water from the vendors at the gate to rinse these bottles. Empty test tubes (used to draw blood samples) are difficult to purchase, and laboratory staff ask colleagues working in larger hospital laboratories in Freetown to provide them, which they clean and re-use until they break. The basin does not have running water, and instead a rubber bucket next to it is kept full. Drawers on the floor, where rats and cockroaches scurry, are used to store reagents.

The lab does a wide range of tests, including microscopy tests (i.e., the Widal test for typhoid, malaria blood smear, sickle cell test, liver function test, urinalysis, tuberculosis sputum and stool analysis, and blood grouping) and rapid diagnostic tests (for hepatitis B, diabetes, haemoglobin, syphilis, H pyloric, faecal occult, malaria). The lab staff normally buy rapid diagnostic tests (RDTs) and the reagents necessary to conduct microscopy tests from other hospital labs. Some supplies are bought from a relative of one laboratory worker, who owns a private laboratory and works as a middleman and distributor for the Belgian diagnostic manufacturing company Cypress Diagnostics.

Despite frequent written requests and the formal existence of a district budget for laboratory supplies, the government provides few laboratory materials beyond malaria RDTs and tuberculosis (TB) microscopy reagents. The laboratory charges patients at fluctuating rates, with the total price of a common combination of tests (malaria microscopy, haemoglobin, Widal test for typhoid, and urinalysis) ranging from between 25,000 to 50,000 leones (1.75–3.50 GBP) depending on the negotiation skills of the patient or paying party. According to government policy, malaria testing is supposed to be free of charge. The community health centre (CHC), however, quickly runs out of the few malaria RDTs they receive from the National Malaria Control Programme, and even pregnant women and children under five years old (who are supposed to receive free care under the Free Health Care Initiative) are usually asked to pay a standard charge of 25,000 leones for their combined tests. To make up for the government shortfall, laboratory workers buy additional malaria RDTs from pharmacies and supplies for malaria microscopy from private diagnostic sellers. In order to make a return on these investments, they increase the price of other tests.

Patients are charged a total amount, offered no breakdown of costs, and are not given receipts. When a test is ordered but turns out to be unavailable, the

laboratory staff will charge the patient, take their sample, and walk with the sample to the private hospital next door. There they will ask the resident laboratory technician to perform the test and provide them with the result, which is then recorded on a laboratory results form and given to the patient. The patient in question, meanwhile, is not informed about the stock situation—this is to prevent the health centre from losing future business.

On arriving at the lab, all patients are referred by the laboratory technician to AHF's HIV clinic for 'other tests'—the nature of the testing is purposefully obscured because of the perceived stigma attached to HIV testing. When a patient returns from HIV testing, they hand over their medical form, which now includes the HIV test result, to the lab technician and sit down in the corridor to wait for their name to be called. Meanwhile, the lab technician looks over the medical form to check the test(s) decided upon and then calculates the price. The patient, or any accompanying relative, is then asked to pay for the test(s) before continuing. The laboratory technicians work together to test each patient one by one, which means that the testing process might be very quick (around 20 minutes) when there are few patients, or much longer (one hour or more) when there are multiple patients waiting in line. Whilst carrying out their work, the laboratory staff sometimes chat with patients and crack jokes, but they never explain what kind of tests they are performing.

Laboratory results are documented by hand and kept in a single laboratory ledger. The results are copied onto a laboratory results form, which is then folded, closed with staples and carried by the patient back to the community health officer's (CHO's) office.

Handling results

The next step in the diagnostic pathway is for the community health officer (CHO) to integrate test(s) results with the clinical gaze based on an interpretation of patients' signs and symptoms. Gathering data on this step was one of the more challenging aspects of fieldwork as the CHO would not convey much explanation about test results to the patients who Fatmata followed. At times, they would even embellish a diagnosis in order to make a profit on privately procured medications.

Patients must wait in the hall outside the CHO's office until they are called in. When it is the patient's turn, they hand their laboratory results form to the CHO, who then provides basic information regarding the diagnosis: for example, 'You have an infection' when the patient has an STI infection, or 'You are malaria- and typhoid-positive', or 'Your blood is short' (meaning the patient's haemoglobin is low). Sometimes, the CHO will question the laboratory result. For example, when he received a haemoglobin test result that far exceeded the normal range, he

mentioned to the patient that he did not trust the result and sent her to the private hospital's laboratory next door. Similarly, patients will often question the common 'malaria-typhoid' diagnosis many of them receive, but only (for the most part) in their own homes (where field interviews took place). Only one patient observed openly questioned the malaria-typhoid diagnosis she received in the CHO's office, but this was because the patient had already received the same diagnosis at other hospitals and the prescribed medication had not alleviated her complaints.

The health centre's limited number of diagnostic tests and its unreliable supply chain mean that there are few investigations undertaken into patients' underlying conditions; meaning that diagnosis is almost always based entirely on those diagnostic tests that are readily available rather than those that would be best suited given the patient in question's symptoms and medical history. When the CHO distrusts a test result or suspects there is an underlying condition, they might prescribe another medication not linked to the actual test result.

After laboratory results are communicated, the CHO asks the patient if they are 'ready' for treatment; in other words, if they have money to pay for the medicines. The CHO charges the patient a total amount without specifying the costs per medication and directs the patient to the treatment room.

The treatment room

The treatment room is the final stop in the patient pathway and is situated next to the waiting hall. Its door is always locked and access is controlled by a private medical assistant, who sells medicines in the hospital and treats the patients that the community health officer (CHO) sends. The medical assistant does not have any formal medical training and works as a volunteer at the health centre, but his father is a lab technician in the health centre and he has been working in the treatment room since 2015. By watching nurses and CHOs, he has learnt to administer medicines and perform circumcisions, and he uses these skills (or rather the public perception of these skills) to earn money by selling medicine. The medical assistant purchases medication in bulk from pharmacies. The CHO then buys them directly from the medical assistant with the money he received from patients. There are no receipts provided to patients and haggling is common.

The medical assistant dispenses his medicines from plastic bags onto a metal trolley. The price of his medicines varies between CHOs and depends on the assistant and CHO's prior transactions and interactions. As with diagnosis, malaria treatment is supposed to be free, but because of insufficient supply of malaria drugs, the CHO at times broadens malaria diagnoses to malaria-typhoid so as to justify charging patients for treatment. Patients who were interviewed complained

about the high prices of treatment, and some complained that the health workers were more interested in earning money than caring for people.

There is little to no information provided to patients about which drugs are prescribed for which diagnosis; similarly, patients are often left unaware of what kind of intravenous (IV) therapy they are to receive (most patients are provided with antibiotics for typhoid or a urinary infection). Several patients who Fatmata observed did not come back for follow-up treatment, possibly because of the way they'd been treated at the health centre. Patients with infected wounds are not sent to the lab; instead, one of the CHOs will assess the wound in the treatment room and ask the CHO-in-charge to review and determine the price of the treatment. Depending on the severity of the wound(s), they might charge anywhere between 150,000 and 200,000 leones (10.50–14 GBP).

After the initial treatment has been dispensed, little attention is paid to ensuring patients return for follow-up treatment or attending to the patient if and when they do return. Follow-up treatment usually occurs over a three-day period and typically includes intravenous therapy or injections. Patients who take oral medications are not booked in for follow-up visits.

Patients who are asked to come back for IV or injections show the medical form they bought during their first visit to one of the nurses sitting in the waiting hall. The nurse will send the patient directly to the CHO's office and the CHO will look at the form, date it, and tell a nurse to administer the follow-up treatment in the treatment room. If the patient is not better after three days then they are sent for laboratory tests again or else are referred to larger public hospitals in Freetown. The high cost of receiving a malaria-typhoid diagnosis and prescription—around 250,000 leones (17.60 GBP), equivalent of half the minimum monthly wage in Sierra Leone—deters patients from coming back to the health centre, with some not finishing their three-day dose of antibiotic injections. Instead, some patients opt to buy over-the-counter drugs from pharmacies or unlicensed 'drug peddlers', skipping the testing process altogether, or else save or borrow the money necessary to visit a larger hospital or private laboratory.

Concluding remarks

This ethnographic account of diagnostic work in Sierra Leone has shown that diagnostics are used not only because they are needed to inform diagnoses and treatment decisions, but also because they have an economic value for the laboratory staff and health workers who purchase and sell them. As such, there is an incentive to over-test, which increases the economic burden on patients. Erratic and sparse government supplies to the studied laboratory turned laboratory workers into entrepreneurs and active actors in making diagnostic testing

available. This in turn affected the diagnoses patients received, as laboratory staff and health workers occasionally embellished diagnoses (most commonly diagnosing malaria-typhoid instead of just malaria) in order to charge patients for diagnostics and medication which ought to have been provided for free.

Diagnosis in the health centre was limited and depended entirely on which diagnostic tests were available when patients visited; diagnosis was rarely based on tests that corresponded to patients' actual symptoms or medical histories. Furthermore, the interpretation of test results by health workers tended towards more drug-based interpretations, as such treatment plans could raise money for health workers, who would then be able to purchase medications from pharmacies and sell them back to patients at marked-up prices.

Our anthropological exploration of this community health centre provides new insights into the different values attached to diagnostic work in Sierra Leone and reveals that, when diagnostics are reduced to their economic value, their medical value—as well as public trust in healthcare institutions—are undermined.

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