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Citation for published version:

Vernooij, E, Koker, F & Street, A 2021, 'Responsibility, repair and care in Sierra Leone's health system', *Social Science and Medicine*. https://doi.org/10.1016/j.socscimed.2021.114260

Digital Object Identifier (DOI):

10.1016/j.socscimed.2021.114260

Link:

Link to publication record in Edinburgh Research Explorer

Document Version:

Publisher's PDF, also known as Version of record

Published In:

Social Science and Medicine

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ARTICLE IN PRESS

Social Science & Medicine xxx (xxxx) xxx



Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed



Responsibility, repair and care in Sierra Leone's health system

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ARTICLE INFO

Keywords: Repair Responsibility Care Patient pathways Diagnostics Sierra Leone Health system

ABSTRACT

Central to the workings of a hospital are the technical and bureaucratic systems that ensure the effective coordination of information and biological materials of patients across time and space. In this paper, which is based on ethnographic research in a public referral hospital in Freetown, Sierra Leone, conducted between October 2018 and September 2019, we adopt a patient pathway approach to examine moments of breakdown and repair in the coordination of patient care. Through the in-depth analysis of a single patient pathway through the hospital, we show how coordination work depends on frequent small acts of intervention and improvisation by multiple people across the pathway, including doctors, managers, nurses, patients and their relatives. We argue that such interventions depend on the individualisation of responsibility for 'making the system work' and are best conceptualised as acts of temporary repair and care for the health system itself. Examining how responsibility for the repair of the system is distributed and valued, both within the hospital and in terms of broader structures of health funding and policy, we argue, is essential to developing more sustainable systems for repair.

1. Introduction

'If the system doesn't work, you have to make it work for you, for the sake of the patient.'

(Consultant Physician speaking to the junior doctors on her ward.)

What does it mean to 'make' a health system 'work for you'? What does the assertion that a health system is not working tell us about normative expectations of how a health system *should* work? And how can ethnographic research into the everyday practices and relationships involved in 'making' the system work help generate new conceptual and normative frameworks for understanding what a health system is and should be?

At Connaught Government Hospital in Freetown, where we carried out the ethnographic research on which this article is based, staff often described the challenge of caring for patients in the face of an absent or broken system. Health workers pointed to a chronic shortage of essential equipment and resources, including diagnostic machines, laboratory reagents, and essential medicines, as major impediments to the accurate diagnosis of disease and the effective treatment of patients. But beyond noticeable material absences, health workers also described the less visible daily grind of working to coordinate care across different people,

departments, institutions, and technologies in the busy hospital when 'systems don't work'.

Patient care is always temporally and spatially distributed in a hospital: biological samples are extracted from patient bodies and transported to the laboratory (and in some cases private laboratories off-site), and multiple specialist doctors who move between patients' bedsides depend on medical files to ensure that important information is shared. Medical sociologists have described hospitals as sites where intensive 'articulation' and 'mobility' work are necessary to ensure that people, resources and knowledge are effectively configured and ordered across time and space (Bardram and Bossen, 2005; Strauss et al., 1982).

In Connaught Hospital, descriptions and experiences of health system failure are often rooted in breakdowns in the temporal and spatial coordination of patient care. Samples went missing, lab results were not collected, a stamp was put on the wrong form or medical files disappeared. These small instances of breakdown were rarely dramatic or climactic events. They did not compare in emotional weight, for example, to moments when doctors had to triage scarce resources, such as when one junior doctor had to 'play God' by deciding which patient should receive the only oxygen machine on the ward. Nonetheless, health workers were aware that frequent small lapses in coordination could have huge ramifications for patient outcomes.

https://doi.org/10.1016/j.socscimed.2021.114260

Received 13 February 2021; Received in revised form 8 June 2021; Accepted 21 July 2021

Available online 22 July 2021

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While health workers at Connaught often found the conditions under which they worked deeply demoralising, on numerous occasions we witnessed people make unscripted interventions in patient pathways in an effort to improve their trajectories. We observed many small, mundane acts that bridged gaps in technical and bureaucratic systems and ensured the continuation of patient care across different departments, institutions and staffs. Such acts included the physical transportation of a laboratory request form to another department, a phone call to retrieve missing information about a patient from another hospital, and the bringing of a patient's sample to a private laboratory (where lab tests are completed) free of charge through a trust fund set up by junior doctors.

This work was undertaken by doctors, nurses and laboratory workers, but also sometimes by patients themselves, their relatives, and in some cases by ourselves as we followed patients for our research. In many cases these tasks were not part of people's formal job descriptions and there was often ambiguity over who or what would complete these tasks if the system 'worked'. These small 'fixes' of breakdowns in the coordination of patient care, we suggest, might be understood as repair work on the health system itself.

To examine the role of repair in health systems, we build on work in infrastructure studies and urban studies that has drawn attention to repair as a 'remorseless and necessary' component of any complex system (Cross and Murray, 2018; Denis et al., 2016; Graham and Thrift, 2007; Houston, 2017). System breakdowns, Graham and Thrift (2007) argue, are not aberrant but are an intrinsic aspect of any complex socio-technical system, and ongoing micro-scale acts of repair are always necessary to hold decay at bay. We find this approach to repair helpful because it is not premised on a distinction between broken and functioning systems; instead, it starts from the position that all systems are subject to entropic forces and require constant acts of maintenance to keep them working. Repair and maintenance studies seek to redress the way in which the ubiquitous and mundane work of repair is rendered invisible in modern life, and call for scholars to engage in 'broken world thinking' that does not take the stability of modern systems for granted but sees them as a constant, ongoing achievement (Jackson, 2014).

Of course, as others working in contexts of chronic resource scarcity have noted, broken world thinking takes on a rather different cast in places where, due to the visibility of technical and bureaucratic breakdown, health workers, users and commentators are quick to label the system as 'broken' (Grant, 2020). In such places, we argue, a focus on repair provides an alternative to a focus on the ruination of postcolonial health infrastructure (Stoler, 2008) and draws attention to the everyday work involved in keeping systems going.

The question of repair is especially important, we argue, because it brings into focus the vital role that people play in a given health system. While repair work might be distributed across humans, tools and technologies (e.g., a diagnostic machine programmed to give an error alert), repair work is rarely straightforward and often requires adaptation, tinkering and innovation, all of which depend on 'human labour and ingenuity' (Graham and Thrift, 2007: 4). Repair studies has emphasised the importance of human improvisation to the work of repair (Henke, 2000; Suchman, 1987), a concept that has also become popular in critical studies of global health, especially through ethnographic accounts of health worker 'resourcefulness' in the face of chronic resource shortages in hospitals in the global south Livingston, 2012; Wendland, 2010. Annemarie Mol's research on diabetic care in a Dutch hospital, meanwhile, shows that experimentation and adaptability-what Mol refers to as 'tinkering'—are also core features of biomedical practice in well-resourced health systems (Mol, 2008).

While our focus on small acts of improvisation and resourcefulness is inspired by these works, we also recognise that the celebration of repair and improvisation as a form of care can divert attention from the 'politics of repair and maintenance' in under-resourced health systems (Graham and Thrift, 2007: 17; Grant, 2020). Central to this politics, we argue, is the question of responsibility. By taking responsibility for

'making the system work', the consultant physician implied in the quotation from which this article takes its cue, one also takes responsibility for the wellbeing of others. But the questions of who is and who should be responsible for repairing the system, or creating one where it is missing, are not always straightforward to answer.

In this paper, we examine in close detail one patient trajectory through Connaught Hospital to reveal moments of breakdown and repair in the coordination of patient care across time and space. We follow the story of Kadiatu, who was admitted to Connaught in February 2019 with a high fever when seven months pregnant. By following Kadiatu's story, we examine the lengths to which people go to 'make the system work' and those instances when the responsibility for repair was not taken, as well as the reasons that might lie behind these lapses. Understanding how the responsibility for 'making the system work' is distributed, who carries its weight and the implications for them and their ability to care for others is, we argue, essential to understanding what a health system is. In the conclusion we offer some suggestions for how repair might be incorporated into health system thinking and how the labour of repair might be supported in under-resourced settings.

1.1. Setting

The health system in Sierra Leone is routinely characterised as a space of failure (e.g. Jackson, 2019). This became especially evident during the Ebola outbreak, when the tragic inability of public health facilities and hospitals to diagnose, isolate or care for patients or to protect health workers was widely reported in global media, often via tragic images and sensationalising descriptions of suffering (Monson, 2017). Sierra Leone's health system is also known for its high infant and maternal mortality rates. In 2010, the government established the Free Health Care Initiative (FHCI) to curb these mortality rates by abolishing all charges at government health facilities for pregnant and lactating mothers and children under five years of age. The FHCI included several reforms, including raising the salaries of health workers to decrease the likelihood of them charging user fees to augment their meagre income (GoSL, 2009). Whilst FHCI received much (inter)national praise during its early years, it was also heavily donor-dependent, with 87 % of its costs funded by external partners (Anderson and Beresford, 2016), and its sustained success has been hamstrung by increasing demands, low staffing, and stockouts of drugs and diagnostic supplies, resulting in high out-of-pocket costs for patients (Jalloh et al., 2019).

Connaught Hospital, where research for this paper took place, is Sierra Leone's main teaching and adult referral hospital. Since its inception in 1909, the institution has been shaped by colonial inequalities and racism, and in recent years has been beset by civil war and multiple infectious disease outbreaks, including cholera and Ebola (Hirsch, 2020). Connaught Hospital is also a highly political space, and during our research, which took place several months after an election, several heads of departments were replaced because of their association with the incumbent party. Despite these challenges, Connaught remains Sierra Leone's principal adult referral hospital. While its patients mainly come from Freetown, or the surrounding Western Area, it's specialist diagnostic and treatment services are also the last resort for patients from across the country whose needs have not been met at a primary or secondary care level.

2. Methods

The research on which this article is based forms part of a wider research project (www.diadev.eu), which explores the role that diagnostic devices play in the transformation of health systems in underresourced settings. In Sierra Leone, the study assessed the role of diagnostic tests in public health emergencies, laboratory strengthening in the Ebola aftermath and how diagnostic practices structure patients' navigation through the health system. Research was undertaken at multiple levels of the health system (community, primary health clinic, district

hospital and referral hospitals) by a multidisciplinary team of anthropologists, laboratory scientists and medical doctors. Research at Connaught Hospital took place between October 2018 and September 2019. Data collection for this paper was carried out by the first author, working as the research coordinator, and the second author, working as a research assistant within the project, in close coordination with the third author, in her role as Principal Investigator. Ethical approval for the study was granted by the Sierra Leone Ethics and Scientific Review Committee and the University of Edinburgh's Research Ethics and Integrity Committee.

2.1. Pathway approach

To understand diagnostic processes in Connaught Hospital we adopted a pathway approach that involved following patients through the institution and mapping the consecutive steps or events they encountered between a beginning and endpoint (e.g., from admission to discharge) (Trebble et al., 2010). Patient pathways (or care pathways) were introduced into health care in the USA in the 1980s to improve service efficiency and care practices (Allen, 2009) and have since become a popular tool in health policy and health services research for assessing integrated care across different parts of a system (Van Houdt et al., 2013). As policy and management tools, patient pathways provide predefined timelines and routes for patient care, and health system research often focuses on evaluating how closely actual practice conforms to that standard. In this formulation, patient pathways are often associated with target-based management to improve operational performances of an organization.

In contrast with managerial approaches, we employ the patient pathways as an ethnographic method to illuminate how patient care unfolds across space in real time. A patient pathway, in this approach, is not a pre-established standard but an emergent and often unpredictable route that a patient actually takes through a health system. Following patient trajectories has a long precedent in medical anthropology, with ethnographers frequently tracking how people move through and between institutions, their relationships with the people and technologies they come into contact with, how they become known to and by others and how these interactions and practices shape the care they receive (Biehl, 2005; Livingston, 2012; Mogensen, 2005; Whyte, 2014). To develop an anthropologically informed patient pathway model we combined the systematic documentation of steps of diagnosis and treatment associated with conventional health systems research on patient pathways with the more open-ended manner of data collection used in ethnographic studies. We developed a structured observational tool to document diagnostic events (e.g., triage, examination, investigation) and their impact(s) on clinical management (see supplementary material - annex A), which was pre-tested and adjusted by the research team for use at different levels of the health care system. This was combined with interviews with patients, relatives and the nurses and doctors involved in their care, as well as unstructured observations, in which we accompanied the patient as much as practically possible and recorded their trajectory through the hospital in real time. The goal was to develop a methodological approach that could be easily replicated and yet also provide a richly contextualised ethnographic account of the relationships and practices that structure patient care.

Our methods also drew from research in science and technology studies that has shown the work of constructing the patient body to be a collaborative (and often contested) endeavour, distributed across people, technologies and hospital spaces (Mol, 2002). Building on this work, we approach 'the patient' as a distributed person encompassing biological samples, documents and verbally shared information that often circulates beyond the patient body, meaning we did not see the patient pathway as confined to what happened at the patient's bedside. Reflecting our conceptualisation of the patient as a distributed person, we distributed data collection between the researchers; the first author focused on the health workers and followed samples to the laboratory,

and the second author concentrated on the patients and/or patient relatives. Our ethnographic approach of studying distributed patient pathways brings visibility to other (human and material) actors beyond the patient, such as the patient relative, referral coordinator, blood samples and lab reagents, which may remain hidden in examinations of standardised care pathways in health management and policy studies.

2.2. Participants and sampling

Fifteen patients who presented at Connaught Hospital with fever (either self-reported or diagnosed by the triage nurse $[>38.0^{\circ}]$) were selected randomly during their triage process upon arrival in the outpatient department of Connaught. Eight of these patients were referred by another hospital and introduced to us via a referral coordinator, who facilitated referrals. The other seven patients were approached by FK, (initials second author), in the waiting room of the triage area. All names referred to in this paper are pseudonyms.

Out of the 15 patients, eight were male and seven were female. All were between 20 and 85 years old. The majority of the patients were either unemployed or self-employed in small-scale business activities. Two people received a free healthcare stamp at the hospital, meaning they were deemed eligible for free diagnostic tests and treatment under the government's FHCI policy. The majority of the 15 patients were severely ill when they presented at Connaught Hospital. Ten out of the 15 were admitted, but only one received a definitive diagnosis confirmed by laboratory tests (tuberculosis). Nine subsequently died. All patients who we followed had previously visited other health providers before coming to Connaught, including primary healthcare facilities, district hospitals, traditional healers or pharmacies. Out of the 15 patients, five had tested HIV positive prior to their hospital visit (one patient also co-infected with hepatitis B), two patients had a pre-existing diagnoses of tuberculosis and one patient had a pre-existing diagnosis of hepatitis B. The high number of HIV-positive patients among admitted patients was in line with a recent quantitative analysis of Connaught, which found that HIV-positive patients represented 40 % of admitted patients at the medical wards (Lakoh et al., 2019).

2.3. Data generation and analysis

During our analysis, the research team made summaries of each patient's trajectory by triangulating the information derived from observations with interview data from patients' relatives, doctors and lab technicians; informal conversations with nurses and data registration clerks and diagnostic information written on patient charts and lab forms. Developing a clear diagnostic story was difficult. Sometimes the timeline described in interviews did not match patient notes; other times the pathway ended abruptly because a patient died before having their samples taken to the laboratory. It soon became apparent that, while we were attempting to build a comprehensive overview of a patient's diagnosis and treatment trajectory, no one involved in their care at the hospital occupied a vantage point from which that story was clearly in view. The story that emerged from checking patient forms and piecing together information from doctors, our own observations and interviews with relatives is therefore a co-production that would not otherwise exist; the patient pathway is an ethnographic story, not a medical 'case'.

In this article we focus on the patient pathway of one patient, Kadiatu, a young pregnant woman who was diagnosed with HIV and hepatitis B prior to her admission and who presented at the hospital with a fever and abdominal pain. We have selected this particular case study because it revealed multiple breakdowns in the coordination of care between and within facilities as well as the range of different actors involved in repair work. In some ways, the story might seem an 'extreme case' because of the multiple failures it revealed. However, an extreme case is often analytically helpful because its extremity makes common dynamics more explicit Gerring, 2007. Indeed, many of the navigational dynamics in Kadiatu's diagnostic pathway were also found in our other

observations, even if in her case the tragic consequences were more visible.

3. Results

Kadiatu, 22, grew up in Kenema, in the Eastern Province of Sierra Leone. Her parents struggled to provide for her and her four other siblings, and she dropped out of secondary school at 17 when her family could no longer afford school-related costs. Kadiatu married a man about 10 years older than her and they moved to Freetown together. Soon after her marriage she suffered a miscarriage and stillbirth, which led to rifts forming between her and her husband and to her moving temporarily back to her parents' home in Kenema. After returning to Freetown and becoming pregnant for the third time at the age of 22, Kadiatu tested positive for HIV and hepatitis B at a community health centre in Freetown. When Kadiatu was admitted to Connaught Hospital, she was seven months pregnant and living with a friend in Freetown following a fight with her husband. She had recently lost her informal nannying job and was being financially supported by her sister, Mariama, who was seven years older than her and who lived in Freetown.

3.1. The provisional diagnosis and hospital referrals

Kadiatu arrived at the Princess Christian Maternity Hospital (PCMH) in Freetown one Saturday in February 2019 complaining of abdominal pains, fever, yellowed whites of her eyes and pain when walking. She was examined by a doctor, who wrote a provisional diagnosis of 'sickle cell disease' on her registration form, and asked her to come back on Monday for several tests (a sickle cell test, a hepatitis B test and haemoglobin), as laboratory tests were not available over the weekend.

When she returned on Monday, the rapid tests were conducted but the results did not confirm the provisional diagnosis (sickle cell disease was negative, HB was 7.8 g/dl and hepatitis B was positive). The doctor who examined Kadiatu noted on her form that the abdominal pain was not associated with labour, and wrote a referral to Connaught Hospital, for 'further evaluation and management', with the expectation that more advanced lab tests and specialised care would be available there. Kadiatu's short referral note simply stated '22 years old, Hep B + RVS [HIV], positive, febrile illness'.

That Monday afternoon, Kadiatu arrived in the outpatient department of Connaught Hospital with Mariama. Kadiatu and Mariama were met in the hallway by Samuel, one of the hospital's two referral coordinators, whose task it is to coordinate patient referrals between primary healthcare facilities, district hospitals and the specialist hospitals in Freetown. Samuel had been on the lookout for Kadiatu; he'd been phoned by the referral coordinator at PCMH who told him that a pregnant woman was on her way.

It was Samuel's job to collect, share and provide information about patient referrals and the availability of beds and services (i.e., blood bank and operating theatres) to help improve access to specialist care. From his small shared office in the entrance hallway, Samuel attended to newly admitted patients or made calls to other patients. When not in his office, Samuel went looking for empty beds while assisting lost patients and alerting specialists of incoming patients. An additional responsibility of the referral coordinator was described in a recent analysis of national referral data: 'advocate for the free health care population to receive entitled free care', as stipulated by the Free Health Care Initiative (Youkee et al., 2020). Whilst this advocating role is not further explained, it suggests a more active involvement is required of referral coordinators than merely providing, collecting and sharing information.

Samuel obtained a free patient chart for Kadiatu at the hospital's 'bank'. After arranging a wheelchair for Kadiatu, he left her to wait in the hallway while he went to the office of the hospital's director to get a free healthcare stamp. When he returned, he dropped Kadiatu's patient chart in the triage room with the nurses and went back to his office to

attend to new incoming patients.

After some time, FK went into the triage room to ask when it was Kadiatu's turn, as she looked to be in increasing pain. Fifteen minutes later, Kadiatu was called to come in. The nurse checked Kadiatu's vital signs and categorised her as 'red', the most severe score on the SATS triage scale, indicating she needed to be seen urgently by a consulting doctor.

Kadiatu, her sister and FK went back to the hallway of the emergency department, where they waited for 2 h to see a doctor. Kadiatu was by now crying and visibly in pain. Finally, a junior doctor named Idris called Kadiatu into the consultation room. Upon seeing Kadiatu and reviewing the patient chart, which stated 'RVS' [HIV], he remarked to FK that, as a severely ill referral patient, Kadiatu should have been sent straight to the medical observation unit, a holding room where a patient is observed overnight prior to full admission. However, no one seemed sure of who should have been responsible for making this happen. In some cases, the referral coordinator was able to shepherd severely ill patients past triage, but he had not been able to accompany Kadiatu because other patients were waiting for him.

After asking Kadiatu some questions about her medical history and performing a physical examination, Dr Idris prescribed IV fluids, IV paracetamol and spironolactone tablets, but no provisional diagnosis was noted on the patient chart. There were no laboratory requests made, which was likely due to the time of day (whilst the laboratory was formally open six days per week from 8 a.m. until 8 p.m., junior doctors would not usually send patients to the laboratory after 5 p.m.).

Dr Idris admitted Kadiatu to the medical observation unit and gave her patient chart to FK, who then gave it to the nurses in the medical observation unit. Kadiatu's sister returned home to collect money to pay for her medication, but when she reached the pharmacy, they only had one IV fluid available. That night, Kadiatu was put on the IV fluid drip but received no other drugs.

The next morning, during the ward round, a different junior doctor, Musa, wrote several provisional diagnoses on Kadiatu's patient chart for the first time, including viral hepatitis, sepsis and pregnancy-induced jaundice. The provisional diagnoses were not explained to either Kadiatu or her sister. Kadiatu's phone rang, and Mariama gave the phone to one of the nurses to speak to Kadiatu's husband. The nurse talked to the husband in a fiery tone and told him that his wife was severely sick and that he needed to come and support her.

Whilst the team of junior doctors and the consultant physicians were seeing other patients, the nurses noted Kadiatu had lost some fluid. They thought her waters had broken and that she was now in labour. The consultant directed the junior doctor to refer her to PCMH since he argued pregnant women should be cared for in the maternity hospital: 'We don't deal with them here'. Kadiatu travelled to PCMH in an ambulance, accompanied by one of the Connaught nurses and EV (initials first author), where the nurse handed over the patient file and explained that the patient had been referred back to PCMH because 'the doctor thinks she is in labour'.

That evening, EV received a call from Samuel, the referral coordinator, who said that Kadiatu had come back to Connaught. Kadiatu's file had gone missing in the transfer and so she had to be triaged again at Connaught; the referral coordinator had to once again get a (new) patient chart stamped by the hospital's directorate with a free healthcare stamp. Since her file was missing and there was no referral note, Kadiatu herself had to communicate to the doctor at Connaught that she'd been sent back to Connaught after it emerged that she was not in labour and that she had received a provisional diagnosis of viral hepatitis at PMCH.

In the first step of Kadiatu's diagnostic pathway, there were several moments of breakdown in the referral system between the two hospitals, leading to delays and Kadiatu being triaged three times over 12 h in two different hospitals. Whilst the referral note and green patient chart with the 'free healthcare stamp' were meant to coordinate Kadiatu's referral process, the process required the active presence, caretaking and intervention of the over-stretched referral coordinator, an independent

research assistant and the severely ill patient herself.

3.2. Accessing 'free' tests

Back at the Medical Observation Unit, Dr Musa considered three possible diagnoses (viral hepatitis, sepsis and pregnancy-induced jaundice) which were based on Kadiatu's medical history (HIV), her presenting complaints (fever, low blood pressure, weakness, yellow colouration of eyes) and previously conducted rapid tests (hepatitis B). He wrote several laboratory requests to access more information about the type of hepatitis and Kadiatu's liver and kidney function.

Having worked as a house officer in the hospital for nearly a year since his graduation, Musa was used to having to wait at least 24 h for test results and therefore requested diagnostic tests at the same time as prescribing treatments. He wrote a new treatment plan in the patient chart, adding ceftriaxone, a broad-spectrum antibiotic, to treat a possible bacterial infection that could cause sepsis (and explain the fever). It was common practice for newly admitted patients to be prescribed either one or two broad-spectrum antibiotics to fight potential infections in feverish patients while they awaited diagnostic results. It was unclear why he did not prescribe treatment for another provisional diagnosis, viral hepatitis, but a likely explanation is the treatment is costly and generally inaccessible except for co-infected HIV positive patients who are being treated at the HIV clinic in the hospital, which was not the case for Kadiatu for reasons that were unclear.

In order to access free treatment under the Free Health Care Initiative, Kadiatu's prescription form needed a signature from the hospital director or the hospital secretary. Hospital managers were often reluctant to sign the forms, however, because the hospital rarely received the promised supplies from the government and instead incurred the costs of free treatment itself. EV accompanied one of the nurses to the director's office. He was on his way out and so the nurse knocked on the door of the hospital's secretary instead. Seated behind his mahogany desk in a large leather chair, the secretary checked the paperwork. Muttering that the patient's name was not written clearly, he seemed unlikely to sign the forms. It was only when the nurse leaned over the desk and pointed out the name of the patient on the medical chart, next to the free healthcare stamp that the referral coordinator had arranged, that the hospital secretary grudgingly signed.

When the nurse and EV presented the signatures to the laboratory technician and radiologist, they both asked curtly, 'Who signed this form?' The radiologist mentioned that he would call the hospital secretary as the ultrasound was not supposed to be free. The nurse said, 'Just tell him we were there with the white woman' (referring to EV). The radiologist then turned to EV and said, 'Tell the woman to drink fluids and come in 30 min'. After leaving the room, the nurse told EV that Kadiatu was a very 'lucky' patient, as normally the ultrasound is not free in Connaught, even for free healthcare patients. However, when Kadiatu and Mariama arrived at the radiology department the next day, the radiologist refused to perform the ultrasound, even after Mariama showed him the same signed request form that the nurse and EV had presented previously. It appeared that, unlike the white researcher, Kadiatu and Mariama were less well positioned to 'make the system work'.

Only later, after spending more time with laboratory technicians, building up rapport and observing everyday life in the laboratory, we learned that because the hospital had not received enough supplies for several months, lab technicians and the radiologist had been buying their own reagents and charging patients for diagnostic services to recoup the costs, see (Vernooij (2021)) for a further analysis of the economic value of lab tests in Connaught. The request that this patient be provided with the tests for free therefore presented a problem for the lab staff and radiologist, who would need to find another way to recoup their money. Other scholars have written about the informal payments underpinning transactions in the Connaught Hospital, reporting that unsalaried staff (routinely referred to as 'volunteers') draw an income

from patients by selling medicines and services (Brooks and Herrick, 2019). However, rather than attributing these transactions as specific to volunteers, our research points to the underlying problem: breakdowns in the government's free healthcare supply chains.

A similar problem presented at the pharmacy. The nurse gave the prescription form to the pharmacist, who took IV fluid from a nearly empty cabinet labelled 'free health care'. IV paracetamol was still not available, and they were told to check back in 2 h. It also appeared that the nurse had not taken the most recent prescription form with her to be signed by the hospital secretary, so the signed prescription form did not include ceftriaxone. When Mariama checked back in with the pharmacy, the drugs were still not available, and the nurses told her she could buy them at a reduced price through them instead. Mariama paid the nurses 150,000 Leones (equivalent to 13 GBP) for the IV paracetamol and 70,000 Leones for another drug (likely ceftriaxone, but Mariama wasn't sure).

In this step of the diagnostic pathway, the breakdown in government supply systems created a gap in service availability which was patched by health workers, who established a quasi-private testing service within the hospital and took on the responsibility of procuring materials. Whilst health workers privately selling diagnostic tests was 'illegal' according to the referral coordinator, it affected nearly every site of medical testing in the hospital, ranging from the triage (where nurses sold glucose tests) to the laboratory and radiology department.

3.3. Handling test results

The laboratory technicians wrote the results of the investigations they carried out on Kadiatu's samples on slips of paper and left them at the reception desk to be picked up. However, the movement of paper between the ward and the laboratory was not straightforward. Junior doctors wrote lab request forms in the ward, but it was not always clear who was responsible for transporting them to the laboratory. It was similarly ambiguous who was responsible for collecting lab results. We observed while at the laboratory reception that this was most often done by patients' relatives, but frequently they were not informed that they could pick up the lab requests themselves. Sometimes patients did not have relatives to do this for them, leading to delays in getting results back. According to one of the consultant physicians, making sure lab results were picked up was the responsibility of the junior doctors—but, she explained, some of them were not actively following up and were instead asking nurses to collect results.

In Kadiatu's case, FK informed Mariama that she should go to the lab to request the results so that they could be passed on to the doctor, enabling the doctor to get them back relatively quickly. However, in other cases, the makeshift system for transporting forms between clinic and lab frequently broke down. A few days after Kadiatu's initial medical test results were received, for example, Dr Musa wrote another lab request for further HIV-related tests, including a CD4 count and CrAg, to ascertain the state of Kadiatu's immune system. However, the HIV-related lab tests which had been written on the patient's chart were either not copied onto a lab request form or the lab request form was not brought to the lab (Dr Musa did not remember which) and therefore the tests were not delivered.

While the laboratory request form is designed to coordinate care across the different departments, in practice active work by laboratory technicians, nurses and patient relatives is necessary to ensure the forms actually move around the hospital. Constant attentiveness and follow-up by health workers are necessary to make the system work. Forms, stamps and signatures are essential for diagnostic work, but this work also requires initiative from those involved in patient care to ensure such bureaucratic artefacts reach the right people and achieve their intended

Sometimes, as we saw in the nurse's attempts to obtain a signature for free tests and medicines, the work involved in getting tests done does not only involve writing or transporting forms but also social persuasion.

When the results of Kadiatu's laboratory tests failed to confirm a provisional diagnosis of viral hepatitis, Dr Musa advised Mariama to try to find the 250,000 leones necessary to conduct an ultrasound to check Kadiatu's liver function at a private laboratory. Since the radiographer insisted on charging Kadiatu for the scan, the doctor reasoned she might as well get it done privately, as the scan would be of better quality. Mariama did not have the money herself and tried calling Kadiatu's husband. In an interview, she mentioned the husband visited the hospital twice, but did not speak kindly to Kadiatu. Whilst he was 'dressing well', he did not pay for her treatment. This aggravated one of the doctors; Mariama recalled a doctor telling Kadiatu's husband, 'You come to this place, and you don't even try to say sorry to her; you come here all dressed up, and if anything happens to her you will be held responsible, and the soul of this woman will hunt you'. However, these efforts at shaming a relative into taking responsibility for Kadiatu's care, in lieu of the provision of free healthcare by the government, ultimately failed, and Kadiatu never had an ultrasound scan.

3.4. Final diagnosis

Unable to get a laboratory-confirmed diagnosis for viral hepatitis, Musa concluded he was going to continue managing Kadiatu for one of the other provisional diagnoses: sepsis. He explained in an interview that sepsis can be caused by any type of infection (bacterial, fungal, viral) but, as blood cultures were unavailable, there was no way to ascertain a bacterial infection, so he was managing her for sepsis caused by her HIV infection. He continued his ceftriaxone prescription and added another broad-spectrum antibiotic, metronidazole (Flagyl), to cover a possible urinary tract infection, following the result of a urinalysis test. Furthermore, he prescribed intravenous paracetamol and iron tablets.

On a Saturday night, one week after she first went into the hospital, Kadiatu gave birth in Connaught with her sister at her side, but without any midwife to assist her (as midwifery care is provided in the maternity hospital, but not in Connaught). According to Mariama, she was not helped by the nurses in the ward. The child did not cry when she was born but, according to Mariama, was breathing. Kadiatu was relieved and told her sister she was thankful to God for helping her deliver her baby by herself. As they were rushed to the maternity hospital, the baby stopped breathing.

According to the maternity hospital, Kadiatu did not have any delivery-related complications and, on Sunday morning, they sent her back to Connaught Hospital again. Until this point Mariama had hidden the fact that the baby had died as she was worried the news would affect Kadiatu's wellbeing—but, when Kadiatu kept asking her about the baby, she finally told her the news. Mariama said that Kadiatu turned her head away and did not speak again until she passed away the next day.

When a patient dies, their chart is first kept in the mortuary and then moved to the hospital's medical records office. One of the main challenges for the registry clerks, they explained, is that about 95 % of the times there is no final diagnosis filled in on the patient chart. This was the case with Kadiatu's file, and so the registry clerk looked for the 'presenting complaints' box, found 'HIV/hepatitis' written there and entered this as the final diagnosis.

Each of the three doctors involved in Kadiatu's care mentioned different possible causes of death; none were certain about it. Musa, the junior doctor, thought she died of sepsis, but the consultant physician thought it was an acute pulmonary embolism. Yet, another doctor who was volunteering with the international charity King's Sierra Leone Partnership (KSLP) instead suspected acute liver failure, which was not confirmed by the lab results (but then, he also second-guessed the lab results and did not think an acute pulmonary embolism matched the symptoms). According to Mariama, Kadiatu was killed by the knowledge of her baby's death. Mariama was not informed by the doctors of her sister's possible diagnosis or cause of death.

All the health workers involved were upset about Kadiatu's passing

since she was a young woman who had been 'ping-ponged' between two hospitals, as the consultant put it. Kadiatu was not the only pregnant woman who had passed away in Connaught—just a few weeks earlier another pregnant woman with a fever had died who'd been referred by the maternity hospital. The consultant therefore wanted to discuss the 'case' with the hospital's director to find solutions. Since the medical notes from Kadiatu went missing during her travels between the hospitals, we sat down with Dr Musa and the KSLP doctor and made a summary based on our notes and their memories. When EV met the consultant a few months later, he said he now had the phone number of the director, who had told him that if anything like this happened again, he could immediately phone him for assistance. Thus, having the phone number of the hospital's director was seen as another way to 'make the system work for you'.

4. Conclusion

Our efforts to piece together Kadiatu's diagnostic pathway revealed many instances in which she was failed by the health system. Bureaucratic confusions about whether Kadiatu was a maternity or general patient, limited free healthcare drugs and gaps in laboratory capacity hampered a timely diagnosis and prevented the delivery of adequate specialist care. Yet according to one consultant, individuals were not to blame for these failures in care because 'people have to be directed by a system'. They need management and supervision, he explained, but also the 'means' to do what is expected of them. Indeed, our research suggests that, in many instances, people are not so much the problem as the solution, especially when they intervene in moments when the responsibility for carrying out coordination work is unclearly allocated or under-valued.

When referral patients were triaged urgently, when tests were conducted and results received or when hospital managers signed forms, the system 'worked' because people had made the effort to ensure that Kadiatu's care was coordinated across and between institutions. In some instances that work involved transportation: carrying papers around the hospital to get signatures from the hospital managers or to bring lab requests to and from the laboratory. In other cases, it involved fastidious attention to detail: ensuring that the correct treatment prescriptions were presented to the pharmacists and laboratory tests were added to the correct forms. Yet in other instances, this required the work of bureaucratic persuasion (as when the nurse pointed out Kadiatu's name on the medical chart and thereby removed the last reason for the hospital secretary not to sign the form) and moral persuasion (as when the doctor tried to shame Kadiatu's husband into paying for private tests). Finally, it also involved entrepreneurship, as when laboratory workers and radiographers addressed the gaps in medical supply systems by establishing private testing businesses within the public hospital (although these businesses were not effective at plugging the gaps in the free healthcare system).

Social studies of biomedicine have drawn attention to the ways in which diagnosis and care are coordinated (or not) in well-resourced and under-resourced settings (Berg, 1997; Engel et al., 2017; Mol, 2002; Strauss et al., 1997; Street, 2014). We argue that, when coordination work is undertaken as a makeshift, ad hoc intervention, it is best understood as a form of repair. By looking at how patient care is coordinated through a repair framework, attention is drawn to the small and mundane acts that are part and parcel of making a system work (Grant, 2020). To some extent, everyone has to do this work because technical and bureaucratic systems always require improvisation and tinkering in order to operate under particular conditions. But focusing on makeshift coordination work in an under-resourced setting also draws attention to the politics of repair involved in 'making the system work', i.e. the ways in which responsibility and capacity for repair are distributed between people and across institutions.

One of the limitations of a pathway approach is that the focus on individual trajectories can conceal some of the structural factors

involved in specific care interactions, such as gender, race or ethnic inequalities (see for example Mogensen, 2005). However, a granular analysis of those pathway interactions can also provide insight to how people's particular social status and position in the institution impacts their ability to undertake repair. The referral coordinator, for example, seemed uniquely well-positioned to carry out system repair, in part because he was not attached to any single department in the hospital and because he often had oversight of the patient's interaction with the health system prior to admission. But referral coordinators in Connaught were over-stretched, receiving calls from other referral coordinators 24 h a day, including on their one day off, meaning they were often tied to their desks and unable to accompany patients through the institution. Doctors and nursing staff, who in many cases already felt under-valued and under-compensated for their work by the Sierra Leone Government, similarly struggled to find the additional energy and time needed to 'make the system work', even as doctors included this edict in their informal training of medical students. As anthropological studies undertaken during the Ebola epidemic have shown, feelings of underappreciation (i.e., of the personal and social sacrifices of performing risky work), limit people's willingness to take responsibility (again) for the system (Park, 2017; Parker et al., 2019; Richards et al., 2019).

The failure to incorporate system repair into a medical division of labour or to recognise it as consequential work across the hospital hierarchy, meant this work was often devolved to the people least-well positioned to do it, that is the patient or their relatives. Kadiatu and Mariama were young women with limited education, had little authority with the hospital staff and did not know how the hospital system worked, and yet, despite being poorly positioned socially to carry out repair work effectively, they also took the most responsibility for doing

As anthropological researchers whose job it was to piece together the diagnostic pathways of the observed patients, we also found ourselves in a powerful position to pass crucial pieces of information on that could help coordinate care, especially when patient charts went missing. This capacity raised ethical dilemmas about the extent and limit of our own responsibility to conduct repair work when confronted with breakdowns of the system. Important here is that the capacity to contribute to repair was unevenly distributed across the research team. It was more acceptable for EV (a white female anthropologist from the Netherlands), to take on the health worker role and accompany and ask questions to senior clinicians (and to get answers), than it was for FK (a black female lab scientist from Sierra Leone). The ethics of providing assistance to patients was also complicated by the fact that the member of the team who directly witnessed the implications of system breakdown for patients, FK, was a research assistant on the project who was herself embedded in a project hierarchy. Whilst we intervened by paying for food for patients and sharing information and accompanying patients, funding conditions did not permit us to pay for medication and tests, which FK often found difficult in terms of her own relationships with and sense of responsibility for patients and relatives.

The question of when and where anthropologists might have responsibility for system repair ultimately led to questions among the team about how the structures of international health research place responsibility for negotiating the ethics of repair at an interpersonal level onto the most junior and precariously employed members of the team. The event of Kadiatu's death had a significant impact on both EV and FK, casting a shadow over their remaining time in the field and raising questions about the ethics of conducting international and anthropological research in extremely under-resourced settings.

But the politics of repair and responsibility also go far beyond the hospital walls or the parameters of health research. In particular, we saw how responsibility for maintenance and repair of the Free Healthcare Initiative was distributed away from government (and international donors) and transferred onto hospital management. While our study focused on relationships of repair within the hospital, there is also a need for further attention to the historical relationships that structure the

funding and implementation of health policy and consideration of the role that repair might play in these relationships (Anderson and Beresford, 2016). The historical involvement of western countries and international organisations in Sierra Leone's health system, including the continuing legacies of colonial governance, slavery and racist healthcare policies, also raises questions regarding the responsibility of countries that benefitted from those historical arrangements to contribute to the resourcing of system repair in the present. It is pertinent, perhaps that 'reparation', which is often used in calls for financial amends to be made for slavery, also means the 'action of repairing something'. Our research inside the hospital has shown that repair is best understood as a relationship of responsibility for the care of others, and this arguably equally applies to repair at the level of international health funding and national healthcare politics.

One problem with the concept of repair is that it suggests the return of what is being repaired to a working state, yet given Connaught's unstable history and political status it is difficult to point to an original state of functionality. The repair work we observed often generated a temporary and ad hoc solution to a given problem. This work was often not supported by institutional resources, was not recognised by management and was not supervised to ensure it took place. This meant that it was also unreliable, as patients could never be sure that a test that was ordered would be administered or that results would be received, that they would get the free healthcare stamp they were eligible for or that they would receive the medicines that had been ordered. In this sense, the work we described taking place in the hospital might be better understood as a temporary 'patching up' of the system rather than repair or maintenance, both of which imply there is something continuous and self-sustaining at play.

A key question is therefore how the work of patching up patient coordination—that is, 'making the system work'—might be transformed into more reliable forms of repair. How can repair of the system be translated into a system of repair? If routine repair is integral to making any health system work then it also needs to be recognised and valued in health system models, policy and planning. Yet models of health systems that focus on building blocks and functional inputs leave little space for the ongoing in-between work of technical and bureaucratic repair that is necessary to keep any system going. Newer more nuanced models emphasise linkages between the intangible 'software' components of a system, including institutional relationships, values, norms and 'hardware' components such as surveillance, infrastructure, medical supplies, workforce and communication technologies (Palagyi et al., 2019), and we would argue that anthropology has a valuable contribution to make in this area in terms of understanding the relational aspects of repair. Since system repair hinges on people taking responsibility for the wellbeing of others, for example, it is especially important that we consider how the people who work in health systems might be better supported to take that responsibility on. This entails going beyond the conceptualisation of health workers as 'human resources' - functional inputs equivalent in kind to health information systems or essential medicines (WHO, 2007)- to consider the ethical, social, physical and economic burden that 'making the system work' places on people.

More concretely, given that coordination work is often the casualty of health worker over-work and stress in under-resourced settings, it makes sense that this work is recognised through delegation to a specific professional role such as that embodied by the referral coordinator in Sierra Leone. A challenge, however, is that the referral coordinator programme started as a donor-funded project in the aftermath of the Ebola response and governments often struggle to regularise externally funded projects when the funding stops. But since March 2021, after being funded by external donors for nearly 6 years, the referral coordinators in Sierra Leone are now included on the government payroll and integrated within the Ministry of Health and Sanitation. While our research showed that it is also imperative that referral coordinators are given the time and space in which to do repair work effectively, the integration of this programme into the health system can be seen as a

hopeful starting point in the recognition and resourcing of relationships of repair.

Author contributions

EV: Methodology, Investigation, Formal analysis, Writing - Original Draft, Writing - Review & Editing, **FK:** Methodology, Investigation, Formal analysis, Writing - Review & Editing, **AS:** Funding acquisition, Conceptualisation, Methodology, Formal analysis, Writing - Original Draft, Writing - Review & Editing.

Acknowledgements

Research for this article was undertaken as part of the 'DiaDev: Investigating Diagnostic Devices in Global Health' research project (www.diadev.eu). This project has received funding from the European Research Council (ERC) under the European Union's Horizon 2020 research and innovation programme (grant agreement no. 715450). We are grateful for the support of Dr Ann Kelly, Dr Boie Jalloh, as well as King's Sierra Leone Partnership, and Connaught Hospital's management, laboratory staff, health workers, and patients and their relatives, in particular Kadiatu and her sister, who shared their time and insights. We thank Dr Daniel Youkee and Dr Abdul N'Jai for their feedback on earlier drafts. Finally, we wish to acknowledge the invaluable support of Benjamin Bangura, who assisted with participant referral in his capacity as referral coordinator, and passed away in Connaught Hospital shortly after our research was completed.

Appendix A. Supplementary data

Supplementary data (the structured observation tool) to this article can be found online at https://doi.org/10.1016/j.socscimed.20 21.114260.

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