Stitching Infrastructures to Facilitate Telemedicine for Low-Resource Environments

Rajesh Chandwani  
Indian Institute of Management  
Ahmedabad, Gujarat (India)  
rajeshc@iima.ac.in

Neha Kumar  
Georgia Institute of Technology  
Atlanta, Georgia (USA)  
neha.kumar@gatech.edu

ABSTRACT

Telemedicine can potentially transform healthcare delivery in low-resource environments by enabling extension of medical knowledge to remote locations, thus enhancing the efficiency and effectiveness of the larger healthcare infrastructure. However, empirical studies have shown mixed results at best. We present a qualitative investigation of a long-standing telemedicine program operating from Lucknow (Uttar Pradesh, India). Invoking the lenses of human infrastructure and seamless spaces, we highlight the factors that determine the success of this telemedicine program. We identify and describe three important aspects: (1) conceptualizing telemedicine as the connectedness of two nodes rather than doctors and patients alone, (2) identifying the critical ‘carrying agent’ (local doctors at peripheral nodes) and engaging them in program design and implementation, and (3) ensuring co-creation by engaging patients in the process. Finally, we discuss how our lenses allowed us to recognize the seams made visible through the juxtaposition of the infrastructures at the central and peripheral nodes, and to emphasize the human elements that addressed these seams for ensuring the facilitation of a successful telemedicine program.

Author Keywords
Health; Telemedicine; India; HCI4D; ICTD

ACM Classification Keywords
H.5.m. Information Interfaces and Presentation (e.g. HCI): Miscellaneous

INTRODUCTION

There is a significant rural-urban divide in the Indian healthcare system. About 75% of the healthcare facilities in India, also accounting for infrastructure and manpower, are located in urban areas, but serve only 27% of the country’s population [2, 27]. This divide is unlikely to be mitigated in the near future, given the pattern of investments in healthcare, which project that—in 2022—the number of hospital beds per 1000 will be 3.8-4.2 in urban areas as compared to 1-1.2 in rural areas [10]. The lack of manpower is mainly at the specialists’ level, with about half the posts for surgeons, gynaecologists, paediatricians, and physicians lying vacant in rural areas [3]. Information and Communication Technology (ICT) interventions such as telemedicine have the potential to act as conduits of information and offer promise towards bridging the rural-urban divide in healthcare provision [12, 46].

Telemedicine entails remote delivery of health-related services through transfer of audio, video, and graphical information via ICT, and includes both diagnostic as well as consultative services [35]. It can potentially enable the extension of modern medical knowledge, and thus, can help in the provision of accessible, affordable, and quality healthcare services to remote inaccessible areas [25, 36]. In addition, it can facilitate diagnosis, treatment, preventative health advice, health education, as well as training for patients and healthcare workers. Review studies on telemedicine have also emphasized that telemedicine initiatives tend to reduce the cost of healthcare service delivery and hence can augment accessibility and affordability [7]. Research conducted in low-resource environments such as those in India has reiterated the cost-effectiveness of telemedicine. For example, Meher and Kant [23] examined the economic benefits of telemedicine in the All India Institute of Medical Sciences (AIIMS, New Delhi). Their findings affirm that telemedicine saves both time and money, and could thus be especially valuable for patients from rural areas. Apart from providing medical advice to patients in remote regions, telemedicine has been leveraged towards augmenting the knowledge and skills of healthcare professionals through continuing medical education (CME), training and development of paramedical personnel [26], and for enhancing effectiveness of public health programs through data collection and analysis (e.g., GPS-enabled data collection for mapping epidemics).

Researchers, however, have emphasized that evidence regarding the effectiveness of telemedicine is unreliable [8]. Many ICT initiatives for healthcare fail to achieve desired outcomes [41]. One crucial aspect that leads to less than optimal results in this regard has been the unidirectional focus on the technological and medical aspects of service design and delivery and insufficient emphasis on human and social dimensions such as doctor-patient interactions and health-seeking behaviors in society [21]. Arguably, telemedicine tends to amplify the effectiveness and efficiency of existing healthcare delivery or the lack thereof [45]. It has the potential to influence existing social, cultural, and technical aspects of health systems and,
in turn, existing infrastructures can influence the adoption and evolution of the technology [15]. Even if telemedicine can technically connect rural and urban nodes, however, it is the assemblage of various social, cultural, and technical components that adds complexity. For example, the socio-cultural context of a remote rural setting entails local interpretations of diseases, medical facilities, and technical infrastructures as compared to those at the central nodes. Similarly, the diversity in technological, institutional, and medical contexts can amplify complexity.

The points of juxtaposition of these distinctly diverse contexts act as seams [43] rather than strict boundaries. According to Vertesi, “seamfulness posits that each system lies in messy and even unarticulated local overlap with other systems,” and these seams, indeed, provide for opportunities where designers can architect an alignment. In this paper, we examine a telemedicine implementation and study “how to patch the complexities to create an alignment” across the seams in an e-health context [43]. An important determinant of effective telemedicine is the relative interpretation and use by participating actors (mainly doctors and patients, but also other staff and/or family members). The interpretations and behaviors of these embedded actors, in turn, are determined by the design and implementation of the technological system and its alignment with aforementioned sociocultural aspects. This means that, while technology plays a part, the process of alignment across the seams is determined by the design and implementation aspects related to the human infrastructure [34]. Understanding these human and sociocultural dimensions of telemedicine is important for effective design and implementation of telemedicine. However, in case of telemedicine, as highlighted by Whitten et al. [47], “We know a good deal about bandwidths and resolutions, but little about the human dimensions that make practice possible.” We attempt to address this gap by examining the telemedicine system as a seamful context and invoke the human infrastructure lens to understand how design and implementation can enable alignment across (and in spite of) these seams.

We present an analysis of a telemedicine implementation at the National Institute of Medical Research (NIMR) in Lucknow, Uttar Pradesh (India)\(^1\). This initiative has been widely considered to be successful and we investigated aspects of the system that allowed for overcoming the challenges of the seamful context through human infrastructure design and implementation, and how these aspects played out. We discuss implications for telemedicine and e-health initiatives in low-resource environments across India, emphasizing the importance of addressing the seams, and also recognizing that the rural-urban healthcare divide is prevalent in several other developing and developed regions of the world.

Our paper is organized as follows. In the next section, we detail the context within which our study was situated, describing the present state of telemedicine in India in general and at NIMR in particular, before we lay out the mechanics of the telemedicine program that we studied. We follow this up with related work. After presenting our methodology, we lay out our findings, highlighting the human infrastructures—the different stakeholders in their diverse roles—that the NIMR telemedicine program consists of. We then discuss how these infrastructures were stitched together for facilitation of the telemedicine program, analyzing the seams that the program addressed with human infrastructures for an effective and efficient implementation. The perspective offered by our analysis can be of use to other telemedicine implementations in low-resource environments in particular, but also to programs of a more general nature that might aim to use technological means for bridging distinct contexts such as distance learning, among others.

**BACKGROUND**

We now provide context for our study, describing what telemedicine means for healthcare in India, the origins of the program we studied, and the goals it was intended to serve.

**Telemedicine in India**

We studied the telemedicine system in the department of surgical endocrinology in the super-specialty public health institute NIMR, located in Lucknow, the capital city of the state of Uttar Pradesh (UP), offers a wide range of specialty and super-specialty medical services to a large and growing population not just from UP, but varied and remote locations in India. In addition to providing access to super-specialty health-care services, NIMR also conducts medical research relevant to the services it provides.

The healthcare system in India is a three-tier system with primary health centers (PHCs) at the village level, community health centers (CHCs) at the taluka or sub-district level, and a civil hospital at the district headquarters, offering primary, secondary, and tertiary care services respectively. Super-specialty services are provided in designated centers of excellence such as the All India Institute of Medical Sciences (AIIMS) in New Delhi and NIMR in Lucknow. Patients with complicated diseases requiring super-specialty treatments are referred through the three-tier system to these centers and can go to them directly. However, as these centers are characterized by a heavy inflow of patients and are located in select large cities that might require extensive (and expensive) traveling, patients typically prefer to be treated locally when possible. Further, cultural gaps, including language barriers, between local contexts and large cities render access to the centers in these cities more difficult. These aspects make tertiary care hospitals in India challenging to access, particularly for patients who are remote. Telemedicine has the potential to enable seamless connectivity across the different tiers of healthcare in India and thus enhance the overall effectiveness and efficiency of the system.

Telemedicine was initiated in India by a private healthcare institution, Apollo Hospitals, in collaboration with the Indian Space Research Organization (ISRO) to provide healthcare services in a village called Aragonda in Andhra Pradesh. Consequently, the government departments got involved: ISRO, Department of Information Technology (DIT), Department of Health and Family Welfare (DHFW), Ministry of External Affairs (MEA), National Informatics Centre (NIC), and

\(^1\)Names of organizations have been anonymized.
the respective state governments. These government bodies collaborated to expand the network of telemedicine across the country. Six premier teaching institutes were made central hubs. NIMR was one of them.

NIMR

With the financial support of the state government and DIT, a School of Telemedicine and Biomedical Informatics (SoTBI) was established at NIMR. SoTBI offers diploma courses titled Telemedicine, Hospital Information Systems, Public Health Informatics, Nursing Informatics, and Digital Medical Library. Several projects have been initiated at SoTBI with the aim of covering wide application of ICT for enhancement of healthcare delivery, such as telemedicine consultations to Orissa, supporting medical education through ICT, connecting NIMR to ambulances that can tackle crises at crowded locations such as festival celebrations, and others.

The telemedicine initiative we studied was designed to connect NIMR with state medical colleges in Orissa, located in South-East India. The scheduled tribes who account for roughly 22% of the state’s population, most of whom are low-literate and poor. The medical colleges in Orissa, which acted as peripheral nodes for the telemedicine set-up that we studied, provided specialty services such as general surgery but did not have super-specialty services such as surgical endocrinology and radiotherapy. Therefore, several patients with thyroid cancer were referred to super-specialty institutions such as NIMR for treatment and subsequent follow-up. Several thyroid cancer patients from Orissa, who required surgical endocrinology and radiotherapy interventions, would have to travel to NIMR, more than 1200 KM away, to seek treatment. This travel time is more than 24 hours and involves substantial costs for the patients due to traveling expenses, loss of wages, boarding, lodging, food, among others.

Responding to the high influx of patients from rural Orissa, the heads of the departments of Surgical Endocrinology and Radiotherapy (both were originally from Orissa) considered initiating a telemedicine set-up that would link NIMR with peripheral centers in Orissa so that patients from Orissa could access super-specialty services without incurring travel expenses. Most thyroid cancer patients would require a detailed assessment, a possible surgery and/or radiotherapy, a strict follow-up schedule, lifelong adherence to medication regimes, and repeat laboratory assessments. Physicians at NIMR proposed that a telemedicine system be designed to provide follow-up consultations for thyroid cancer patients as per monitoring needs on the basis of specific blood reports, looking for symptoms, and checking for adherence to the prescribed schedule. Thus, after undergoing primary treatment in the form of surgery and/or radiotherapy for thyroid cancer at NIMR, subsequent follow-up consultations could be held using telemedicine. Extensive training on management of thyroid cancer was provided to the general surgeons from the medical colleges in Orissa at NIMR by super-specialists (at NIMR) who were part of the telemedicine program. Doctors, paramedics, coordinators, and technicians were also trained in the technical aspects of the system’s operation. Funded by the central government, the telemedicine system connecting NIMR and Orissa is a well-equipped, advanced system with high-end Polycom² cameras, and runs on custom software for telemedicine consultations.

The Mechanics of Tele-Consultation at NIMR Consultations were scheduled to be held on fixed days of the month—the second and fourth Mondays for Surgical Endocrinology and the second and fourth Wednesdays for Radiotherapy. The coordinators at NIMR ensured that the lists of follow-up patients were shared with the coordinators at the peripheral nodes. These coordinators, in turn, ensured that patients were informed well in advance about their upcoming appointments and were ready with the required lab reports. The patient reported to the primary physician/surgeon at the peripheral node on the specified day, equipped with required pathology reports and case-related documents. Coordinators on both ends ensured that the system was functioning and that there were no connectivity issues by checking the system on the day before and day of the consultation.

At the specified time, communication would be established between the peripheral node at the respective medical college and NIMR. At the peripheral node, the primary physician/surgeon, coordinators, and patient were present. The team at NIMR consisted of the super-specialist, coordinators, and resident doctors. Both the central and peripheral nodes had a detailed account of the patient’s illness, the treatment that had been received in NIMR, and that which had been advised on prior follow-ups.

During the consultation, the patients and/or their relatives directly interacted with the super-specialists. In some cases, where specific medical aspects needed to be highlighted, the physician/surgeon at the peripheral end contributed to the discussion. The super-specialists began with informal pleasantries, inquired about the general condition of the patients, and then asked pointed questions regarding specific parameters or treatment. If the super-specialist felt that a particular examination was required, such as a throat examination, he/she would ask the physician/surgeon at the peripheral node to perform the same. The super-specialist would then type the prescription and provide a digital signature. The physician/surgeon at the peripheral node would hand over the prescription and explain the dosage of drugs to the patient. This would be followed by a detailed discussion among the super-specialists and the primary physician/surgeon about the patients seen as well as plans for the next tele-consultation.

RELATED WORK

Telemedicine initiatives have been recognized for their potential to enhance the accessibility and affordability of healthcare service delivery to remote rural areas [7]. Several studies have investigated the benefits of telemedicine for healthcare delivery such as enhanced quality of medical consultation [14], reduction of travel costs [29, 38], savings because of fewer requirements for hospital admission [5], as well as improved triage and reduction in length of stay in hospital [48]. Other researchers have posited that telemedicine augments the professional networks of healthcare providers.

²www.polycom.com
While the studies above have looked at parameters related to healthcare delivery, other researchers have examined the challenges related to the introduction of technology in particular, such as challenges in implementing wireless technology [1] and the lack of reliable power as well as technically-trained personnel [42]. Scholars have additionally highlighted several technology-related challenges in implementing telemedicine, such as poor quality of audio/video [14], unreliable connectivity [29], and complexity of the system that limits its usability [38].

Human-computer interaction (HCI) researchers have also examined sociotechnical aspects such as doctor-patient interaction over virtual media [24] and patients’ perceptions regarding virtual doctors [22]. In 2012, Kolko et al.’s study of the adaptation of a portable mobile ultrasound system in underserved hospitals reported multiple barriers to the provision of remote ultrasound to rural locations, such as lack of technological and network infrastructure, lack of trust among actors, diverse work practices, and sociocultural barriers [16]. Other HCI research has emphasized nuances related to the professional nature of healthcare service delivery and the importance of sociocultural aspects of the contexts in which these interventions are implemented [4]. As telemedicine connects diverse contexts, the subtleties of local practices and processes need to be accounted for [32]. Thus, the nuances of the contexts in which telemedicine is implemented are important determinants of the effectiveness of the system, and the same telemedicine system in different contexts may yield very different results [13]. HCI research has not yet deeply explored the issues emerging from extension of medical services across under-resourced regions and the challenges that emerge as diverse contexts are juxtaposed [4, 6, 16, 18, 31]. This is the gap that our work addresses.

Different theoretical lenses might be invoked to illuminate key aspects of telemedicine across contexts. For example, a sociotechnical systems perspective could highlight the interdependence of social and technical aspects involved in providing tele-consultations. However, our focus is on highlighting how the rural-urban divide is bridged by NIMR in connecting the Orissa medical colleges to the tertiary unit in Lucknow, for co-constructing a ‘seamless’ patient experience. Thus we invoke the lens of seamfulness and posit that the context of telemedicine for delivering tertiary care—to connect patients in remote rural areas to super-specialists in the urban tertiary care unit—entails messy and unarticulated overlap between the urban tertiary care system and the local healthcare system [43]. This juxtaposition entails seamful spaces that emerge when attempts are made to layer technology interventions atop pre-existing assemblages that they connect to and extend [37]. The delivery of healthcare in such situations involves life-critical discussions and the need to share complex medical data, and hence requires considerable and careful communication between doctors and patients, working around the seams.

Our research scrutinizes the human infrastructures that successfully connect disparate environments in such seamful contexts. Overcoming the challenges of the seams entails, as we find, involving specific human actors in the design and implementation of ICT. Surana et al. found, in their examination of the rural wireless telemedicine system in South India initiated by Aravind Eye Care System (AECS) [42], that the most important challenge was to deal with frequent breakdowns and maintenance requirements that emerged from aspects such as poor quality power, poor connectivity, remote locations, and lack of local expertise. To overcome these challenges, AECS developed a three-tier support system consisting of local staff for basic maintenance—local network integrators (vendors trained in solving major issues) and a remote management team (skilled professionals). Luk et al. examined ICT interventions to enhance remote consultations in Ghana and found that the adoption and evolution of two distinct ICT interventions was heavily dependent on the selection of partners [20]. Kolko et al. posited that ultrasound could work smoothly in standalone clinics of Ugandan midwives but face considerable challenges when the design involved collaboration with specialists from referral hospitals [16]. These studies highlight the criticality of human infrastructures for overcoming the challenges of seams across various dimensions—sociocultural, technological, and/or infrastructural. Building on prior work in infrastructure studies, Sambasivan and Smyth contributed to the field of Information and Communication Technology and Development (ICTD) the human infrastructure lens, for examining technology adoption and use in contexts that are relatively technology-poor [34]. Our goal in this paper is to further develop this lens as we foreground the articulation work performed towards seamlessly stitching together infrastructures for overcoming the challenges in delivering healthcare in low-resource environments.

**METHODOLOGY**

Our methodology was driven by our purpose to derive key insights for designing an effective telemedicine system by examining how a telemedicine interaction takes place, what the connection between local and remote elements entails, and how the system could be made effective. Given the diversity of actors involved, putting a telemedicine process in place involves paying attention to not only the technological and medical aspects but also the social and human aspects. For attaining a better understanding of a telemedicine interaction as the complex embedded phenomenon that it is, it is important to undertake an in-depth inquiry of the process, examining contextual nuances and allowing for a situated under-

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1http://polhn.org/
standing to emerge, rather than approaching the study from a predetermined set of theoretical frameworks [51]. Since our study explores how and why kinds of research questions, and our focus was on understanding the processual dynamics of the phenomenon, we adopted a qualitative approach to collect and analyze our data [51].

Data Collection
We contacted the head of the department of SoTBI at NIMR and explained the purpose of our research and our proposed plan for data collection. We then visited NIMR on the days pre-specified for teleconsultation (both surgical endocrinology and radiotherapy days) and witnessed their process on 11 days. Of the 62 teleconsultations that we witnessed, 49 were follow-ups and 13 were primary consultations. We deepened our understanding of the implementation by conducting in-depth interviews with the super-specialists and residents at NIMR (5), coordinators and support staff at NIMR (8), surgeons and physicians at the local medical colleges (3), coordinators and support staff at the colleges (4), and patients and relatives at the colleges (16) in order to explore their perspectives regarding the telemedicine interaction as well as to clarify any issues that needed explanation.

This work took place only after multiple (university and hospital) approvals were sought and granted. Before each session we observed, we informed patients and family members present about the purpose of our research and what the (minimally intrusive) process of data collection would entail. We informed them that these observations would have no bearings on their medical treatment, that they could opt out whenever they wished, and then sought their (and the family members’) consent. After this introduction, we witnessed the consultation process seated away from the camera’s line of sight. No patients showed any discomfort. An additional reason may have been that the telemedicine consultations were never one-on-one; coordinators were present on both ends at all times to ensure that links were working, etc. Further, topics discussed were not as sensitive or linked to social stigma as others (e.g. sexual/reproductive health) may have been. Patients were not given any compensation, as the hospital supervisors recommended.

Data Analysis
We adopted a qualitative approach to analyze the data. Though initially we thought our focus would be on the doctor-patient interaction over virtual media, we found that the pre-consultation arrangements and post-consultation discussions between the actors at the two nodes contributed significantly to our understanding. Thereafter, we made sure that we observed the arrangements of the settings, pre-preparation work and post-consultation interactions as well. The data were then coded by both authors independently. The first author is a medical practitioner while the second is an HCI researcher. The diversity of the researchers’ domains ensured that the data was examined through multiple perspectives.

The first step in the analysis was coding, which entailed extracting a categorization of the data, recognizing patterns, and systematically arriving at concepts and themes. The coding was done manually. We began with ‘open coding’, extracting relevant categories and themes. The first-level codes were intrinsically linked to the empirical data, e.g., ‘peripheral coordinator checking the system’, ‘conversation in vernacular language’, ‘super-specialists discussing the findings with the surgeon at the periphery’. In subsequent rounds of coding, we moved from raw empirical data to conceptual and general explanations, that is, from data to theory [19]. The data analysis was an iterative process going back and forth between data and theory, identifying recurring patterns, exploring new and emergent themes, and examining relationships between the concepts. The final concepts and themes were arrived at through mutual discussion among the researchers. They were presented to a number of physicians and residents who were involved in the tele-consultation process for their feedback. The analysis that follows includes this feedback.

FINDINGS
There are three main themes that emerged from our analysis of the telemedicine set-up at NIMR that we detail below. These included (1) telemedicine as a coordinated interaction between the central (NIMR) and peripheral (Orissa) nodes and not the patient and doctor alone, (2) the importance of the role played by the stakeholders at the peripheral nodes, and (3) the importance of patient engagement in the process.

Extensive Center-Periphery Coordination
The video recordings of the pre-consultation preparations and post-consultation conversations highlighted the criticality of the efforts put in by the coordinators on both ends. Coordinators at both nodes assembled approximately an hour before the consultation began. We observed that they followed a protocol and (1) checked the technical aspects of the system (see figure 1), (2) ensured that all prior data of the patients on the list was available at both nodes, and (3) confirmed that all relevant actors, doctors, and patients had been informed. In
checking the system, they made sure that all functions were enabled, including audio/video data transfer and the prescription process. They also checked that all information regarding the patients were present at both ends and arranged in the order in which the patients were scheduled to consult. Coordinators at the central node checked to see if all patients had been informed and how many of them were expected to arrive. Coordinators at peripheral nodes then shared information regarding their phone conversations with the patients and identified the patients who would not be attending the teleconsultation. The relevant files were then removed (at both ends), after which the coordinators tallied the lists again. After they had each gone through their checklists, they indulged in informal conversation with each other. Conversations between the coordinators at both ends was friendly as they chatted about issues they had each faced. Our interviews affirmed the importance of the level of coordination between them. Doctors also recognized that the coordinators had a most vital role to play in the successful implementation of the telemedicine initiative. Dr. Mishra (Head, Department of Surgical Endocrinology at NIMR) said:

“These (coordinators) are the backbone of the telemedicine system. I mean that they run the show. I have my patients, my OPD timings, and my scheduled surgeries. I don’t get time to think about technical aspects, whether the connection is there, camera is functioning, etc. They ensure all of that. I just walk in the consultation room, the patient is ready, the files are up to date and the residents brief me about the case. It is same like seeing the patients in my chamber, well almost... (smiles).”

Given the efforts that both the patients and the doctors must make in order for the teleconsultation to be a success, extensive coordination is required on both ends of the interaction. Though they are prepared for anything to go wrong at the last minute, of course, the coordinators check to make sure that there are no connectivity glitches beforehand. As per Mr. Yadav, the lead coordinator of telemedicine at NIMR:

“We need to address multiple issues to make the teleconsultation process a success. These patients travel from far off rural areas to the respective medical colleges to attend the tele-consultation. We can’t afford any technical glitches. We double-check the connectivity aspects a day before and a few hours before the actual consultation time. I am in constant touch with the coordinators at the other end.”

As we observed, the planning required is not only on the technical end, but also with regards to the individual actors who are to participate in the tele-consultation. As Ms. Garima, one of the coordinators at NIMR added:

“We make sure that all the preparations for the tele-consultation are done well in advance. It requires a lot of planning from both sides, here as well as the medical colleges. We discuss with the super-specialists here and prepare a list of patients according to the follow up dates given to them. Thereafter, we share the list with our coordinator colleagues there in Orissa.”

In Orissa, on the other end, the coordination involves substantial offline work. As evident from our observations and video recordings, one of the main tasks of the coordinators was to ensure that patients were informed regarding their tele-consultation date well ahead of time. Patients were told to get the prescribed tests completed in advance so that when they attended the tele-consultation, the report was ready. Some of the patients needed to travel to the appropriate medical college and planning may have been required. Further, across many parts of the state of Orissa, facilities for getting all kinds of tests completed are limited. Coordinators make a special note of patients coming from such locations and ensure that they are informed well in advance. Mr. Dutta, the lead coordinator at one of the medical colleges added:

“Once we have the confirmation that the tele-consultation is going to happen on such and such date and time, we have to make a lot of arrangements. We ask for the list of patients and once we receive the list, we contact each and every patient and confirm the appointment. We also ask them if they have undergone the tests that were prescribed to them in the previous visit or at NIMR.”

The processes followed by the coordinators at both the central and peripheral nodes ensure that the clinical and technical aspects are checked and ready so that the doctors’ acutely constrained time is subjected to minimal overheads. Central to our findings was this articulation work [39, 40] performed by the coordinators that was primarily offline to ensure that online processes were carried out without glitches. To ensure connectivity and infrastructural stability, often problematic in the settings we studied, the peripheral node needs to be located where basic infrastructure such as electricity, hardware, and internet are at least moderately reliable. The choice of medical colleges as peripheral nodes in our initiative was driven by these concerns. The patients, however, came from even more remote locations and needed to be informed well in advance about the date/timing of tele-consultation so they could make arrangements for travel and get necessary exams done on time. This, in turn, was required for optimal utilization of super-specialists’ time, which was again a major constraint in a low-resource setting. This extensive offline coordination was critical for ensuring that the tele-consultation process did not exacerbate conditions for doctors.

Local Doctors as Key Stakeholders
The video recordings made evident the extensive involvement of the physicians/surgeons at the peripheral nodes. These physicians/surgeons, trained in thyroid cancer care at NIMR, played an active role in the case discussions. During the consultation if the super-specialists required an examination to be performed, they requested the physician/surgeon to do so. For example, in one case we observed the physician examining the neck of the patient for the appearance of nodes on being asked by the super-specialist. The body language of the super-specialist and the physician/surgeon evident in the videos reflected the level of trust between them. After each

\footnote{Names of individuals have been changed for anonymity.}
consultation, the physician/surgeon at the peripheral nodes discussed the findings with the super-specialist. Decisions regarding treatment were also taken collectively. The prescription would be typed in by the super-specialist after each consultation and handed over by the physician/surgeon, who also explained the protocol in detail to the patient in their vernacular. After all the tele-consultation interactions between the super-specialists and the patients were completed, the physicians/surgeons at the peripheral nodes discussed the cases with the super-specialists. The discussion was centered around any new findings, atypical cases, and/or other academically interesting findings observed on that day. We noted that these post-teleconsultation sessions between the super-specialists at the central node and physicians/surgeons at the peripheral end were highly academic in nature.

The telemedicine design at NIMR ensured extensive involvement of the local physicians/surgeons. In the initial phases of system implementation, the physicians/surgeons from the local medical colleges were trained at NIMR in the medical and surgical management of thyroid cancer. The training was provided by the super-specialists in NIMR. Doctors from Orissa had an opportunity to interact with the super-specialists at NIMR and with the coordinators. They were also able to have a first-hand experience of the telemedicine system from the central node’s perspective. The training not only ensured their involvement and upgradation of knowledge and skills, but also led to the building of relationships with the super-specialists at the tertiary level. As Dr. Patnaik (senior surgeon at one of the medical colleges in Orissa), explained:

“We learned a lot when we came to NIMR. As you know, for doctors, continuously uprating their knowledge and learning new things is so important for personal satisfaction. We were trained by Dr. Mishra in surgical endocrinology. I know about the management of thyroid cancer patient and can even perform the surgery. I did not learn these things in my medical college.”

As Dr. Mohapatra (a physician at one of the medical colleges in Orissa) added:

“We continuously learn and upgrade our knowledge about thyroid cancer during these tele-consultations. I look forward to discussing difficult and atypical cases with Dr. Mishra after the sessions are over. It is like a CME (Continuing Medical Education) program for us. Actually much more than that as here we are involved in the treatment protocol design, it is more active than a routine CME.”

One of the most important stakeholders (and perhaps least emphasized in most telemedicine initiatives) that we identified was the local doctor—the physician/surgeon at the peripheral node. Notably, prior studies [30, 17, 33] have highlighted the importance of the primary care physician or family physician in the successful implementation of telemedicine initiatives, the most important factor being the family physicians’ awareness about the local context, culture, language, their understanding of the patients’ requirements, and the patients’ faith in their family physicians. Our research extends this understanding to emphasize that apart from the above cited reasons, the local physician’s involvement from the perspective of upgrading knowledge and skills is important. This is particularly valuable for low-resource environments, where the opportunities for upgrading this knowledge are limited. Research has further highlighted that trust is critical for successfully implementing medical systems in remote areas [16]. We also found that the design and implementation of telemedicine at NIMR resulted in the involvement of physicians/surgeons as well as in building trust between them and the super-specialists.

Patients’ Involvement
We observed (and also confirmed from the video recordings) that patients were confident and fluent in their interactions with the super-specialists. Most of them who had attended the teleconsultation process repeatedly were very comfortable in using the technology. This was evident in their interactions; for example, they faced the camera and not the screen. One striking finding was the extensive involvement of the patients in the process of telemedicine, specifically the effectiveness of their communication with the doctors on clinical matters such as in relating their reports, explaining treatment schedules, and so on. An important aspect of patient involvement was the chronicity of disease (thyroid cancer) which required them to become aware of the disease-specific vocabulary used by the doctors and also more knowledgeable about the disease, its symptoms, necessary exams, and possible treatment.

We wished to clarify whether the doctors felt that these patients were more involved than the patients coming directly to NIMR for face-to-face consultation, and if so, why this might be the case. The doctors shared that attempts were made to engage these patients in telemedicine right before their discharge from NIMR. Before being sent home after the surgery and/or radiotherapy, these patients would be made to witness a live teleconsultation process and encouraged to communicate with other patients who were being consulted and to clarify any doubts. An encouraging response from their fellow community members is an important aspect of the patients’ adoption of telemedicine. As Dr. Tewari remarked:
The doctors explained to us that processes had been put in place to engage patients right from the start of their treatment at NIMR. Patients would begin by viewing a live teleconsultation in process and be encouraged to interact with local doctors, other tele-follow-up patients, and coordinators on both ends. This extensive involvement of patients throughout the telemedicine process proved to be critical for the success of the program, as was believed by the local doctors as well as super-specialists. Further, while arranging follow-up appointments at remote sites, coordinators would regularly call patients and remind them to ensure that they were coming for consultation and had their reports in place. These interactions with the coordinators brought the patients to ‘learn’ about aspects related to follow-ups such as the key symptoms doctors would ask for, exams that super-specialists would prescribe and how frequently, the normal range, treatment protocols, and more.

Prior research has highlighted the importance of ‘competencies’ enabling collaborative work [18]. We extend the implication of the term competency to the development of a common vocabulary and understanding between various actors. Over time, most patients had become fully aware of their disease, treatment protocols, and follow-up requirements. The common vocabulary that developed among the peripheral physicians/surgeons, super-specialists, and patients ensured that information regarding the patients’ condition was communicated smoothly between the central and peripheral node via telemedicine. This was in addition to exchanges between actors regarding the hardware and software that were part of the set-up. All stakeholders were evidently invested in ensuring these exchanges. This not only made the process more predictable for all stakeholders involved, but also minimized the overheads required throughout.

DISCUSSION
Our research extends prior work on telemedicine by drawing attention to the human infrastructures that hold this system together across the center and peripheries, against the backdrop of the rural-urban divide. While the urban center has access to technology and super-specialists, these experts are also severely time-constrained [28]. On the other hand, the facilities and expertise levels at rural peripheral nodes are far more limited, in addition to obvious social, cultural, and economic differences as well. By focusing on the human elements of the infrastructures being stitched together, our goal was to magnify the seamfulness of the telemedicine context we studied and call out these seams, while also understanding how they were addressed for the success of NIMR’s program.

“I feel that these patients are more proactive and also more precise. Maybe because whenever we call them to confirm that they are coming for tele-consultation we ask them again and again—have you done these tests, have you got all the reports, please remember what medications you are taking and if you don’t remember the names please bring the medicines along with the files. I think over time they come to know what information is required. We have no such procedure in a typical face-to-face follow up. While the patient is being sent home, we tell them to get the tests done and bring all the reports. There is no prompting that happens before the scheduled date.”

The patients definitely appreciated the importance of staying on top of their health records. One patient mentioned:

“We need to communicate with the doctor. It is not like he is in front of us and can look at our file, see us, and examine us properly. Here it is different, we need to tell him that this is the situation. And when our doctors and coordinators (from medical college) call us and tell us in detail...we tend to learn...they ask specific things every time.”

Their enthusiasm may also have been partially due to the fact that they were aware of the affordances that the teleconsultation was offering them, which they would otherwise not have had access to. Another patient remarked:

“I maintain this diary which helps me to communicate fast with the doctors in the large hospital (Lucknow). I can see that there are so many patients waiting for the tele-consultation process. We know that the doctor’s time is so precious.”

This involvement of the patients was not lost on the super-specialists at NIMR. As Dr. Kiran (Senior Resident, Department of Surgical Endocrinology) noted:

“Initially these patients are slightly skeptical about the use of telemedicine but you see with repeated follow-ups they become pros (laughs). For example, initially they look at the screen while the camera might be at the side but subsequently, they know exactly where to look at...the camera...and they bring their own diaries with all the reports fully updated. They will proactively tell their TSH levels, calcium levels, and the dose of medicine that they are taking. You can’t guess that these patients are illiterate and uneducated.”

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At first glance, it might appear that the urban super-specialist and the remote patient are the two main stakeholders. However, focusing on the larger human infrastructures and the seams where the central and peripheral nodes are juxtaposed draws our attention to other stakeholders and the articulation work performed at the seams to hold the program in place. These analytical constructs helped us understand how an effective telemedicine process should really be conceptualized in terms of the coordination taking place between two disparate contexts—the central and peripheral nodes—rather than a unidimensional flow of information between two key actors alone. Prior research has hinted at the importance of human infrastructures in multiple ways, for example, by highlighting that the lack of technically proficient personnel could be addressed by developing a network of people who could manage technical problems at different levels [42]. Our analytical approach helped us in foregrounding the roles of different stakeholders that make up these human infrastructures, with their diverse perspectives, objectives, and competencies, highlighting thus their contributions towards the success of the NIMR telemedicine program. This analysis follows, as we unpack one seam after another.

**The Seam of Unreliable Connectivity**

Being able to ensure a working connection through stable power supply and internet connectivity at both ends was critical for the success of the program. Since the rural areas where the patients came from could not guarantee these, the medical colleges were chosen as the peripheral nodes instead. This was a key decision since, here, both the technical and human infrastructures necessary were available, although the patients would still need to undertake travel as a result. To ensure minimum possible disruptions to connectivity, three different mechanisms were put in place. It was the humans or the coordinators at both ends who were responsible for checking that all technical equipment was functional and a connection could be successfully established with adequate predictability. They repeatedly checked for connectivity a day before, and then again a few hours before the scheduled tele-consultation. Here we corroborate prior work [29, 42] and emphasize that some aspects of the physical/technical infrastructural challenges might be mitigated through appropriate human infrastructural intervention.

**The Seam of Complex Moving Parts**

Given the distance between nodes—geographic, sociocultural, economic, and more—coordination between these central and peripheral nodes was critical. As mentioned, both the super-specialists’ and the local doctors’ time was acutely constrained, given the sheer number of patients they each saw on a daily basis. Working around this acute time constraint required targeted emphasis towards making the tele-consultation effective and efficient, even at the cost of making it laborious for other stakeholders. This balance was necessary to ensure the collective or globally (rather than locally) optimal solution, and aligns with recommendations made by Surana et al. [42]. Further, the patients, who had little awareness of the disease and protocols, were compelled to travel to the medical colleges, adding to the uncertainty.

These dimensions entail conceptualizing telemedicine as a complex system with many moving parts (low doctor-patient ratios, doctors’ packed schedules, challenges in getting patients to show up, patients not having proper test results or not bringing in the right paperwork) that can jeopardize the effectiveness of telemedicine. These multiple interrelated aspects need to be addressed for telemedicine to work as desired. In the case of NIMR’s program, not only did the coordinators ensure a working connection at both ends, they also made sure that they had done their ‘homework’ to check that every doctor-patient interaction proceeded as per plan. They coordinated the lists of patients who were part of each tele-consultation before-hand, confirmed the availability of both super-specialists and doctors repeatedly, followed up between visits to check that the patients had gotten all tests and test reports that were necessary, and then reminded the patients to bring these reports with them on the day of the tele-consultation. This was important as many patients would need to travel a fair distance to the medical colleges that were the peripheral nodes. All of this due diligence ensured that the coordinators, and thus the nodes, were on the same page, so to speak.

The super-specialists at NIMR recognized the critical role of this articulation work by coordinators towards enabling a telemedicine set-up that aligned with hospital routines and did not pose additional cognitive, emotional, or temporal strain. The work laid the foundation for efficient exchange of relevant information between the center and periphery. Scheduling tele-consultations on particular days of the month ensured that there were enough patients scheduled for each day of consultations to fully utilize the time spent by doctors on both ends. All this helped in limiting the bandwidth required for the doctors to make their evaluations and minimizing changes to their already hectic routines. The choice of implementing the program for chronic ailments rather than those needing urgent attention was also helpful in this regard.

**The Seam of Low Expertise at the Periphery**

One of the main reasons that the telemedicine set-up was needed to begin with was the lack of expertise at the peripheral nodes, that is, among the physicians/surgeons at the local medical colleges in Orissa. These local doctors were ill-equipped, in terms of their training, to deal with complicated cases. They were also not in a position to tend to the technological set-up. However, they were involved right from the initial phases of the telemedicine program design. They were trained at NIMR in delivering thyroid cancer care and in the use of the technology. The training program, apart from enhancing the medical and technological skills, enabled engagement of the local doctors with the super-specialists and coordinators at NIMR. This phase was crucial for subsequent coordination between the nodes. Further, the local doctors’ involvement in program formulation and technology design ensured their active participation from the beginning. These doctors also recognized and affirmed that their participation in the telemedicine program had led to the upgradation of their skills and knowledge with regards to dealing with thyroid cancer patients.
Prior research has highlighted the role of telemedicine in the professional development of local medical personnel such as paramedical staff [27]. A human infrastructure lens, however, entails looking at the telemedicine system beyond the purpose of ‘training’ local staff to their playing a critical role in linking culturally disparate contexts. This requires us to design systems in a way that involve critical stakeholders in the initial design phase and continuously throughout the implementation. The local doctors served as family physicians almost; our research highlights that involving them in the initial design phase can potentially improve both the medical and technological expertise at the peripheral nodes.

The Seam of Low Patient Awareness

A critical aspect that our findings uncovered in the telemedicine set-up at NIMR was the proactive involvement of patients in self-management and their active participation during the tele-consultation process. The common vocabulary generated by proactive patients enabled a bidirectional involvement and made the process more efficient, lowering the doctors’ required bandwidth for participating in the tele-consultation. This finding emphasizes the role of another critical aspect of the human infrastructure—the patient as a co-creator rather than a passive recipient of healthcare. Prior research has highlighted the importance of the active participation of patients in telemedicine [14], positing that an involved and engaged patient is more likely to adopt telemedicine readily [44] and to report greater satisfaction through the process [11]. By highlighting the human infrastructure, our study not only foregrounds the importance of patient involvement for increasing their awareness and acceptance of technology but also finds that patient involvement is a vital contributor to the system. Indeed, we found that involved patients enabled the super-specialists to perform their tasks effectively. Furthermore, the human infrastructure lens also highlights how to enhance patient involvement in such a system. The coordinators’ extensive offline work and developing multiple touchpoints with the patients brought the patients to learn improved self-management techniques and stay involved.

The above analysis examined how the infrastructures present at the central and peripheral nodes were stitched together in the case of NIMR’s telemedicine program, highlighting the contributions made by the human components of these infrastructures. By drawing attention to the aspects of the context that rendered this stitching seamless, we saw how the treatment of these seams by NIMR resulted in a successful telemedicine implementation in an acutely resource-constrained context. There were multiple stakeholders involved at both the center and periphery—the super-specialists and coordinators in Lucknow, and the local doctors, patients (and patients’ families), and coordinators in Orissa. The program ensured that all stakeholders were actively involved and duly informed before, during, and in-between tele-consultations, which was key for ensuring the effectiveness and efficiency of the program. Paying special attention to the seamfulness of the environment, by addressing each of the seams as mentioned above, the program ensured that all stakeholders’ concerns were managed and their constraints balanced so as to achieve the best possible outcome, globally speaking. Through this analysis of NIMR’s telemedicine configuration, our study extends prior research to emphasize the importance of seemingly non-key actors and how they perform key roles for sustaining a successful telemedicine program.

CONCLUSION

We conducted a qualitative investigation of a telemedicine program in India that has widely been considered successful in the Indian healthcare context. This program entailed the provision of tele-consultations for thyroid cancer patients from South-East India (Orissa). The central node was located in a super-specialty hospital in North India (Lucknow, Uttar Pradesh). Our findings unpacked the roles of diverse stakeholders in the human infrastructures that were engaged by this program, both at the center and the periphery. First, we laid out the role of the coordinators who ensured that a working connection was possible and information regarding patients’ conditions and doctors’ schedules was shared and managed effectively in a bidirectional flow. Second, we examined the role of the local physicians/surgeons who ensured that patients were at ease and their concerns were addressed. We also found their medical and technological skills to mature over time. Third, we studied the involvement of patients to highlight how they remained active throughout the telemedicine process (before, during, and in-between consultations) instead of being passive recipients of medical knowledge and guidelines. In addition to detailing the human infrastructures involved in this telemedicine set-up, we studied how the infrastructures at the center and the periphery were stitched together to facilitate tele-consultations. In particular, we drew attention to the seams that were appropriately addressed by the human infrastructures in this NIMR program to allow for seamless facilitation of telemedicine.

REFERENCES


