Knowledge creation practices at organizational boundaries: the role of ICT in sickle-cell care for tribal communities

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Abstract

Purpose—Emerging economies host the largest populations of vulnerable people suffering from genetic disorders such as sickle cell. Healthcare providers serving tribal communities must create knowledge in context to serve them effectively. Technology might intermediate the creation of organizational knowledge at the intersection of tribal patients, frontline health counsellors, and expert physicians, which then might produce context-specific, evidence-based medicine (EBM). This paper explicates and conceptualises the role of information, communication and technology (ICT) in the knowledge management practices of organizational intersections with tribal communities.

Methodology—The knowledge-in-practice approach supports an ethnographic study of sickle cell care practices in the outpatient clinic of a non-profit healthcare organization in Western India. The analysis focuses on ICT-mediated interactional and technological practices among the physicians, counsellors, and tribal patients and families, over the course of yearlong observations, supplemented by informal and formal interviews and archival records. Vignettes, based on diverse episodes, explicate the key knowledge practices.

Finding—Technology-mediated informative interactions can bridge socio-linguistic and interpretive barriers between actors while also providing a generative structure that leads to knowledge creation and longitudinal clinical evidence about a rare genetic disorder. Three specific technology-entwined knowledge practices emerge: *knowing the community*, *persistent interactional engagement*, and *constructing registers of socio-clinical history*. These practices generate organization-wide knowledge about social and clinical dimensions of the genetic disorder. Our findings are presented through vignettes and a model.

Implications—Technology valuably entwines actors, thereby reducing the distance between expert clinicians and tribal patients. To reduce temporal losses of information, introducing social together with clinical registers creates knowledge in practice, thereby generating field-level evidence of a rare genetic concern.

Originality/value- The value of the paper stems from the in-depth ethnographic understanding of the knowledge management practices at a healthcare organisation delivering care to tribal communities. The longitudinal observations on the usage of ICT by various actors in the organization and linking the literature on knowledge management and ICT, are used to develop the model in the paper.

Keywords—Counsellor, Knowledge, Sickle cell, Tribal community, Technology

Paper Type- Empirical

Introduction

Developing context specific effective mechanisms for knowledge management that rely on information and communication technology (ICT) represents an on-going goal for the healthcare sector (Abidi, 2001; Srivastava and Shainesh, 2015; Vial, 2019). Knowledge management practices in healthcare can engage diverse set of actors such as clinicians, paramedic staff, administrators, and including patient community in practices of knowledge creation, codification, and application (Sheffield, 2008). The use of ICT in knowledge management promises to bridge actors' fragmented knowledge (Bruni and Teli, 2007), which becomes immensely more complex when the interface involves rural community locations, especially in developing economies (Chib, 2010). For example, a committee tasked with reviewing tribal communities' health status in India in 2014 found that the lack of culture-specific practices in healthcare organizations created problematic distance between care providers and vulnerable communities. It also identified socio-cultural history as intermeshed within layers of clinical challenges. One of these contextual interfaces, such as in hereditary diseases, pertains to the intersection of tribal patients, frontline counsellors[i], and clinicians, which could lead to the creation of organizational knowledge if supported by ICT.

In particular, emerging economies are home to marginal, vulnerable, culturally diverse populations, in which hereditary diseases such as sickle cell affect as much as 35% of the population (Saxena, Yasobant and Golecha, 2017). However, the lack of effective healthcare infrastructures challenge care provision, and insufficient contextual insights into culture, socio-economic conditions, and unique traditions are common in medico-clinical care approaches (High Level Committee Report, 2018). Therefore, knowledge management for any healthcare organization is daunting, because it must account for both clinical and socio-cultural perspectives of the community. As prior scholars have established (Sheffield, 2008; Tsoukas and Vladimirou, 2001), organizational knowledge structures emerge from the individual level, reflecting people's social resources, patterns of conduct, and communications. This study therefore addresses how ICT facilitates the efforts of a non-profit healthcare organization in Western India, referred to anonymously herein as the Voluntary Service Organization (VSO[ii]), which has been providing sickle cell care to a tribal population since 2011. This setting provides an ideal context in which to explore how ICT might create context-specific knowledge-based evidence, available to stakeholders.

This ethnographic study of VSO reveals ICT engagement in knowledge practices in an outdoor patient clinic for almost a year during 2016–2018. This research leverages a knowledge-in-practice approach (Carlile, 2002; Nicolini, 2007, 2009), which reveals that organizational work at the intersection can be represented by three practices. First, practices pertain to *knowing the community* by listening, exchanging, translating, and interpreting the various meanings of the social and clinical dimensions of the sickle cell disorder. With this knowledge, the VSO can bridge interactional and interpretive divides. By deploying micro-practices, the interactions based on technology-supported exchanges overcome socio-linguistic and interpretive barriers, by creating a bridge between the clinic and tribal patients. Second, *persistent and generative interactional engagement* by deploying ICT creates a knowledge structure that builds on the common ground prepared among the actors. While the technological elements capture the explicit dimensions, tacit dimensions also have an important role in practice. Third, ICT reduces the temporal loss of information by creating discursive digital clinical registers that support the *construction of a gradient of socio-clinical history* over the life cycle of the patient. This specialization in clinical care leads to the creation of a pool of temporal individual registers reflecting personal and community-specific benchmarks that constitute evidence-based medicine (EBM), beyond organizational boundaries.

The focus on knowledge in practice enables this study to make significant contributions. First, intersections of interpretive and social complexities can be a source of generative knowledge structures, when supported by array of information and communication technologies in healthcare organizations. Second, ICT can increase persistent interactions, which extends the clinical scope to include context-specific features in organizational knowledge. In practice tacit dimensions sustains the technology entwined interactions. Third, organizational knowledge practices can create multiple forms of evidence, by reducing the temporal loss of information and creating individual and collective historical registers in the field of clinical care.

The next section reviews prior literature on organizational knowledge management and details the role of ICT, followed by a brief discussion of sickle cell disease among tribal populations of India. After presenting the findings, as a series of vignettes describing patient and counsellor interactions in the clinic, which also integrate evidence from the organizational archives, this study proposes a conceptual framework of the role of ICT knowledge practices and suggests some practical implications and directions for research.

Review of Literature

Knowledge Management: Role of ICT in Healthcare

Knowledge management is a collection of processes and practices undertaken in an organization to create, share, maintain, and manage the organizational knowledge resources (Andreeva and Kianto, 2012). Despite being one of the most important resources for an organization, dispersed knowledge within and outside the organization remains difficult to use effectively (Despres and Chauvel, 1999; Inkinen, 2016). Yet the effective harnessing of these resources enables organizations to employ their intellectual capital optimally. Knowledge management practices also aim to create value for organizations through various social and technical processes, including interactions, information deployment, ICT, and so forth. (Kuhn and Jackson, 2008; Srivastava and Shainesh, 2015; Vaast and Walsham, 2005).

Organizational knowledge creation also emphasizes the role of individuals and organizations for elevating and expanding the tacit and explicit knowledge possessed by various actors (Nonaka, 1994). Knowledge is not solely embedded in explicit forms, such as patents or standard operating procedures; it is also tacit which is contingent on practices (Lam, 2000). The process of knowledge creation itself is tacit, reflecting multiple social processes embedded in the relationships of various actors, within and outside the organization (Nonaka and Nishiguchi, 2001). That is, organizational knowledge emerges out of multiple interactions and collaborations with various stakeholders, including customers, competitors, and communities (Nonaka and Nisiguchi, 2001) which may become embedded in to shared collective knowledge making the communication possible among the members (Brown and Duguid, 1991).

Orlikowski and Robey (1991) propose that ICT has dual aspects in relation to knowledge management: social and material. Subjective human action physically and socially leads to knowledge management practices, through technological resources; in parallel, these practices get reified through institutionalization and use as an organization-wide resource. Technological resources facilitate collaborations and interactions (Carrillo, Passerini and Wu, 2008) by providing avenues for information recording, processing, and communication among internal and external constituencies (Srivastava and Shainesh, 2015). Organization-wide knowledge creation accordingly must factor in practices boundaries across different group of actors (Carlile 2002) while digitally transforming the knowledge (Vial, 2019).

Although ICT systems usually are incorporated in organizations to translate tacit knowledge into explicit and standardized components (Nicolini et al., 2008), they also can have generative roles in organizational practices, which tend to be overlooked (Barley, Treem, and Kuhn, 2018). Translating implicit knowledge by using technology may require new work practices (Leonardi and Bailey, 2008). As an intriguing research area in the knowledge management domain, this study therefore seeks to understand how ICT not only facilitates information integration but also generates information in organizations (Venkitachalam and Busch, 2012). This imperative is especially critical in healthcare contexts, where the patients, frontline actors, and clinicians are viable sources of information to organizational systems.

In the healthcare sector, ICT uses are not novel; in various knowledge hierarchies, they support knowledge creation, development, and application (Martelo-Landroguez and Cegarra-Navarro, 2014; Sheffield, 2008). However, most extant literature addresses developed economies through distal processes such as telemedicine (Nicolini, 2012) and more proximal processes using electronic health records inside the organization (Kane, 2015). In emerging economies, sectors like eye care (Srivastava and Shainesh, 2015) and primary health (Chib, 2010) has received most attention. By focusing on the developing economy, in conjunction with the rare hereditary diseases such as sickle cell, this study investigates a more complex and nuanced view of intermediation by ICT in knowledge practices. In particular, social structures in emerging economies tend to be stratified and faced with linguistic and interpretive challenges for communicating with tribal and rural populations (Basu, 2000, High level committee report, 2014). Furthermore, any knowledge creation efforts must acknowledge the demography and experience of tribal people, who often are bound to traditions and experience deep economic vulnerabilities. This complexity strongly underscores the viability of using practices to explore how to align local views of the rare genetic disease in a tribal community, because such practices can produce opportunities that organizations can leverage though ICT.

In developed economies, healthcare delivery is dominated by professional expertise (Battilana, 2011), and organizational-wide knowledge practices by engaging with local cultural and experiential views has received scant attention (Sheffield, 2008; Spillman and Brophy, 2018). But organizations aspiring to enhance the efficiency of healthcare systems for rare diseases need to integrate fragmented knowledge, possessed by clinicians, paramedic staff, and patients (Bruni and Teli, 2007), including efforts to codify and personalize that information in organizations (Ellingsen and Monteiro, 2003). The current study proposes a practice-based approach (Nicolini, 2007) to identify knowledge practices in a healthcare organization that relies on a collaborative knowledge-sharing structure, involving human actors and technology, to assimilate knowledge and address the tribal community’s struggle with sickle cell disease. Therefore, the central research questions ask:

How can technology intermediate organizational knowledge creation at the intersection of the tribal patients, frontline counsellors, and expert physicians? How can ICT create context-sensitive evidence-based medicine (EBM) for sickle cell?

Situational Report on Sickle Cell Disease

Sickle cell, a genetic blood disorder, results from hemoglobinopathis—red blood cell particles that become hardened and brittle, deforming into a sickle shape, such that they do not last as long as normal blood cells. Among the more than 250 million people worldwide with sickle cell (WHO, 2006), it is more prevalent among certain ethnicities, such that it is particularly common among African Americans (Ballas, 2001) and tribal communities in developing countries (Nimgaonkar et al., 2014). Sickle cell evokes serious clinical complications, including anaemia, vaso-occlusive crises[iii], and ischemic injury[iv], which lead to premature mortality (Nimgaonkar et al., 2014). The pain crisis associated with this disease tends to be unpredictable, so patients require continuous, high quality care. In developed countries, studies show that sickle cell patients often use more emergency services than other members of the population (Yusuf et al., 2010). In India, sickle cell reportedly affects sizeable population as carrier of disease and significant number as sickle cell disease patients among in over 100 million tribal population (Saxena et al., 2017). These tribals or *Adivasis*, who constitute 8% of India’s population, are subject to special provisions for their educational, economic, and protective interests, though many suffer development gaps due to malnutrition and anaemia (HLC report, 2014). Furthermore, experts have not reached consensus regarding the precise epidemic and clinical forms of sickle cell in these tribal communities due to multiple demographic, social, linguistic, and even environmental determinants (Tewari et al., 2015). Moreover, sickle cell manifests in women, children, and adolescents differently, and many sufferers prefer to seek care from alternative healers rather than clinicians. Little systematic evidence exists, reflecting longitudinal studies of life events experienced by tribal patients diagnosed with sickle cell in India (Nimgaonkar et al., 2014; Saxena et al., 2017).

These combined factors highlight the need for an organizational knowledge approach, and VSO provides an ideal context in which to explore knowledge practices associated with managing sickle cell disease, evidence-based longitudinal care, and cohorts of patients. That is, this study explores the knowledge practices adopted by VSO to explicate the role of ICT in organizational knowledge creation and the creation of clinical evidence.

Method

The data collection involved various ethnographic practices in sickle cell care between 2016–2018, using field-based methodologies in association with VSO. The surrounding area is populated by heterogeneous, rural, tribal communities; and the weekly outpatient clinic provides consulting to patients from three states of western India. Since 2011, VSO begun intensive sickle cell program and after 2015 introduction of ICT based processes 1500 patients have been registered.

The data collection effort focuses on two main goals. First, it aims to identify the practices that build the local organizational knowledge about a rare disorder. Second, it seeks insights into how technology influences these practices and produces different outcomes. In studying practices, it is important to observe what people actually do in interactions (Nicolini, 2007; 2009) as it reflects the meaning making and order producing activities. Such methods have been used to study ICT based interactional patterns in healthcare research (Srivastava and Shainesh, 2015).

Clinics characteristically are sites of fragmented, distributed knowledge (Bruni and Teli., 2007; Nicolini, 2011). The observations for this study involve the interactions and shadowing of actors within the outpatient clinic, which in turn support the construction of episodes of knowledge practices. Following Carlile (2002), the study focus is objects that mediate interactions and their outcomes. In this sense, objects refer to material and technologies with which actors work, including clinical tools/machines, communication devices, and information technologies. The outcomes obtained through their use might include initiating or registering patients for their outpatient visits, counselling, diagnoses, recording diagnostic parameters for experts to review, and reminding patients of future visits. To complement these data, the authors also observed the sickle cell ward, which reveals intensive, complementary practices. These specific practices, whether mediated by objects, in combination or alone, or not all dynamically structure knowledge in context.

The first author shadowed patients and counsellors on outpatient visit days (once in a week), shadowed the sickle cell counsellor during routine work days, observed consultations, and attended the research meetings (Refer Table 1). Detailed memos described the discursive episodes, to reflect individual knowledge practices, as well as the interactions of the counsellor who made calls to patients or relatives before and after their visits to the clinic (Refer Appendix A). The author team undertook informal and formal interview with physicians, counsellors, patients, and their relative to elaborate on the practices. The analysis of the interactional pattern in outpatient clinic, interview transcripts, published documents, and archival materials helped reveal the knowledge practices of the organization. The interpretive data analysis (Nicolini, 2007; Schawartz-shea and Yanow, 2012) moved back and forth between emergent identified practices and the data. It was continuously informed by published audio-visual aids and archives that reflect organizational practices. Finally, written vignettes depict the practices and inform a framework of knowledge practices related to sickle cell. In total, more than 100 hours of observation provide the insights to understand the practices; 25 episodes of shadowing patients during outpatient clinic days were recorded.

During visits, patients' interaction points were distributed during the day, for different collective and individual purposes (Appendix A). For example, interactions at registration tended to be individual and relational, unlike the collective audio-visual viewing participated in by patients and their relatives. The technology also varied, from non-interactive for the audio-visual viewing, to more dynamic and interactive tools during the counselling sessions.

To present these findings, vignettes offer an effective mechanism, as is common in practice-based ethnographic studies (Carlile, 2002; 2004). That is, it can be difficult to reflect the range of observations present in ethnographic data, so vignettes are helpful to represent the richness of practices that technology facilitates in relation to sickle cell knowledge practices. The first vignette refers to a young sickle cell patient, for whom the sequence and pattern of interactions (detailed in separate scenes) accurately reflect the distributed, context-specific knowledge practices that the VSO undertakes to achieve various purposes. The second vignette addresses the counsellor's routine attempts to persuade patients to describe their sickle cell and complete scheduled visits. Finally, different observations inform the third vignette, which thus reveals collective learning from history and a group-level analysis of the individual history. Additional vignettes are presented in the Appendix B.

---------------INSERT TABLE 1 ABOUT HERE---------------

Vignette I: Shadowing in Outpatient Clinic

Scene 1

MB (acronym), 24 year male, reached the outdoor patient clinic at about 9:30 am. Last year, while accompanying his sister for her follow-up, he was diagnosed with sickle cell. He was requested by VSO to undergo screening as his sister was found to be carrier of sickle. Since then, he has visited VSO at a prescheduled times; he received a call from *sister Roshni*, counsellor at VSO, to remind him of his visit two days prior. The counsellor offers him a seat and asks him to hand file he is carrying. File contains history of past visits with clinical and demographic details. She carefully reviews the last prescriptions and ask him to join a small group, sitting in the cubicle. The group watches a video[v] about sickle cell management in vernacular language in which the actors are staff of the VSO. Mb exults,

> I have seen this movie before. Here they show this to everyone. Looks at him he is holding his ankle [pointing toward a visual about person in pain]. It happens same way to me. People in the villages would think as if something has struck him and take him to *Bhagat/Bhua* [Local shamanic healers] …. I also used to wonder what happens when the ankle, wrist, and other joints become site of pain.

These audio-visual aids are viewed by the 10–15 people including relatives of the patients in the counsellors' cubicle. The counsellor calls the names of the patients one by one. She is electronically registering the present patients in a Tablet and also filling the visit date in a new sheet in the paper file. In the dialog, she asked:

> Counsellor (C): How are you, brother? Any pain in between [since last visit]?
>
> Mb: Yes.
>
> C: When it happened and where you took help from?
>
> Mb: I was at field [agriculture], slowly I felt pain in my wrist and [point toward leg joints]. I could not work thereafter that day.
>
> C: Were you not taking medicine [vernacular language], the yellow coloured one?
>
> Mb: I was fine, could not see this [coming].

The counsellor updated this information in Tablet in historical information and care seeking page and asked him to describe it further. She also measured his weight, which is recorded too in paper file.

> Mb: I was feeling a bit of pain, but thought it would go. My relatives had come and they insisted on going with them [to a local festival].

> C: See brother, you should not avoid taking *goli* [medicine]. It is dangerous. I see that you needed BT [short form for blood transfusion] three months ago.

The counsellor to remind it more showed him his clinical history by turning pages of his paper file and asked him not to ignore. She also urged him to visit any other clinic in emergency with this file if a crisis were to arise. The counsellor wrote down the prescription of diagnosis for visit and asked Mb to proceed to the laboratory. Meanwhile, number of patients registered is increased to 30 by 10:30.

Scene 2

Mb returns to the outdoor patient area and hands over the diagnostic reports to the counsellor. The report contain HPLC[vi] record of blood sample, liver profile and some more biochemical tests. She informed the first author that this patient's sickle cell ratio have stabilized, compared with last year, when he was hospitalized multiple times, indicating some improvement. To the patient, she explained:

> C: Your report looks good, brother. But do not ignore pain; otherwise you will have to be admitted again. Whenever pain increases call me. My number is written here [pointing to contact details mentioned in file].
>
> Mb: Yes, sister.

By the time, more than 50 patients have registered, and others are watching the video.

Scene 3

At 12:30 in the consulting room, the doctor is sitting and around 10 patients are waiting and holding their diagnostic report and paper files. Children sit with their guardians, mostly women, and the counsellor takes her seat to the right of a long table placed in the centre. The room is a makeshift consulting space, otherwise used for gynaecological exams. The counsellor calls the names of the patients and asks the children to sit with their parents on the chairs. She calls the name of Mb:

> Doctor: How are you, brother? Looks weak … is everything fine? Not eating well now, a day?
>
> Mb: [smiles].
>
> Doctor [turning page of file to locate day's diagnostic report]: Your condition seems fine, but be careful ... in this weather.

Rainy season is believed to increase the pain episodes in general and the counsellor informs that during this season, VSO receive maximum number of indoor admissions with pain crisi.

> C: He was in pain some time ago…
>
> Doctor: How come brother? Not taking medicines?
>
> Mb: I was keeping fine, it happened suddenly that day.
>
> Doctor: You remember, last time I told you not to miss medicines [asks counsellor to remind everyone about the schedule of medicine].
>
> C: Last year, he was admitted 3-4 times, and blood had to be given.
>
> Mb: I visited doctor in my village, and he gave injection.

The doctor asks him to come to a secluded chamber for an examination. The doctor checks his abdomen and asks him to check himself. This is done to educate patient about enlarged spleen, called splenomegaly, which coincide with discomfort. The doctor writes a prescription and asks him to talk to the counsellor again. In that interaction, the counsellor explains the dosage for the medication and the schedule of administration, then enters these details into the Tablet. The medicine is prescribed for three months.

Insights from Vignette

To understand these sequence of activities, the analysis focuses on actors' interactions and the influence of technology (Table 2). Notably, in a situated manner, the video help educate patients and their relatives, using vernacular forms, about multiple dimensions of sickle cell disease. The content depict sickle cell symptoms and thereby translates clinical impacts into a local context. It highlights the hereditary nature of disease, the social stigma prevalent in the community, the emergent nature of crises, and clinical care. In this clinical space, the collective visualization by patients and their families helps reduce the interpretive variation and divide between local and clinical perspectives on sickle cell. The video also identifies hospital staff, which helps reduce people's fear of the clinic, and depicts clinical consulting as a place shared by the physician, the counsellor, patients, and families. The physical features and sequence of interactions in clinics are designed to reduce barriers between experts and the lay community, but the preceding counselling and audio-visual aids also create a conducive environment of empathy and support, co-experienced by multiple visitors to the clinic. One physician thus imagines that patients believe "sharing the space with other patients … gives a sense that I am not alone … there are others like me."

--------------INSERT TABLE 2 ABOUT HERE--------------

By placing pain moments as central to the narrative, the interactions also rely on technology to discursively link a embodied experience to technical insights. Each patient's version of the intensity of pain, its location, and the place, such as agricultural field in vignette, where they experience it determine reflect their construction of sickle cell, signifying the social-functional nature of disease. Counsellors do not discount these mundane details of felt experiences but instead register the experiences diligently in Tablet. Registering such episodes using a technological interface conveys the significance of the experiential accounts. The

VSO's knowledge practices value such experiences as critical input to the framework of care. These elements in interaction are tacitly bound to the context and cannot be ignored in practice. As a senior physician explains:

> Sickle cell is a genetic disease and unique to communities globally … [though] needs genotype correlates with the phenotype … but we cannot undermine how community relates to the pain, we need to talk and listen. At times we struggle … and asking them to express is very important … the severity of pain, its effect, place and … economic hardship … all counts.

Then the physician and counsellors translate the meaning of their current diagnostic readings in combination with past experiences of embodied discomfort. Mutual transfers of social-clinical worlds thus represent technologically mediated accomplishments in practice. The technology and its artefacts stabilize knowledge structures for sickle cell care by supporting the links between clinical meaning and experiential accounts, which then are registered within the body of organizational knowledge.

Furthermore, ICT affects the counsellor's routine care provision. She draws on situated features to encourage patients to watch the video. Considering the diversity of patients, the film connect to the experiences of the audience while educating the group. A patient's assertion that "people in the village feel differently" highlights that not all practices are commonly experienced. During interactions, the counsellor digitally register the account of pain episode and other details between the visit and also notes in the paper file. She is cognizant that each had received a reminder call from her. Reminding and registering the patient creates a continuum of technologically assisted tasks; these reminders account for much of her work day and are critical aspects for organizing the sickle cell care. As one physician recalls:

> We used to collectively visualize that merely mentioning a future appointment [in patients file] will not work … given the social-economic difficulties [in the tribal community] … more persuasion is required. Therefore, the reminder pop up every day the moment counsellor opens her Tablet. She cannot avoid it … now the follow ups are more efficient than before… it is important as we cannot afford loss to follow up.

Vignette II: Shadowing the Counsellor

As noted, the counsellor reminds patients about their scheduled visits in advance. She not only remind patients about next visits but also reconnect with patients and inquire about their lives. Often she speaks to a person other than the patient, as she elaborates

> Women do not have phones with them… they are either at home or in field for *kheti-majoori* (labor work in agricultural field) … then I have to speak to the *bhai* (i.e., husband, relative, or guardian)… and they do not understand and often refuses to visit … I say that I will call in evening again, once you reach home … I carry this [signalling to the phone] all the time ...

Thus, the reminders have social as well as clinical aims. They build regular social links and create a register of the community that the organization can use to prepare a plan of care. Whereas most visits are scheduled three months in advance, physical distance, financial conditions, disease severity, and emergent hospitalization might alter conventional patterns of care (see Appendix B). In this sense, technology helps the organization connect with the community and also discursively increases the possibility of interactions in knowledge creation work. As clinician elaborates,

> We often see a particular patient who finds it difficult to visit even in 3 months. We provide support … like medicines for longer duration … and alerts counsellor to be

> more in touch …train them little more for complications, medicines, what they need to attend more in case of troubles.

The ICT support thus enables clinical delivery of care and interactional sensing of community needs, after a visit to the outpatient clinic. Nicolini (2007) argues that the proximity principle in clinic where actors and objects are co-present gets modified in complex ways by introductions of space, technology and the divisions of work. For example, the interactional richness created by visits can create modified, clinically relevant cognitive abilities among patients and their relatives. Such abilities prove significant for bridging the divide, especially during reminder call to families in distributed, physically distant spaces.

The VSO’s interactional repertoire thus increases with the introduction of ICT in several important ways. First, it supports the inclusion of a much broader range of personal, historical, and clinical dimensions into interactions. Citing historical patterns and clinical aspects creates a shared memory among participants, such as when the counsellors invoke examples of patients by name, to cite their knowledge about place and the degree of pain, among other elements of their personal history. Second, ICT enhances organizational efficiency by adding new dimensions to organizational cognition when patients are at home but still interact with the counsellor. These new social realities inform the organization about how to recalibrate pathways of care to reflect spatially separated interactions. Third, frontline actors’ ability to manage the clinic increases tremendously, because their time and effort can be directed toward the most critical cases.

We label the practices reflected in interactions intermediated by ICT as *knowing the community* and *increasing the interactional engagement.* It signals that ICT at the boundary can bridge the divide between experts and community to prepare common ground. Increasing interactional possibilities in subsequent visits and in-between reminders provide a platform to register social and clinical aspects. Technology does not replace tacit dimensions, which are interactional and bound to practices, but it augments and complements the broad contours of the interactions in *knowing the community*. This emphasis on "knowing" reflects the ways it gets constructed in each interaction, such that organizational practices, through ICT, continue to capture and accumulate variations at individual and collective levels.

Knowing the community resembles a continuous social process of engaging with one another and interpreting individual experiences (Brown and Duguid, 1991). In support of a situated learning perspective (Lave and Wanger, 1991), learning represents a process of becoming socialized in a particular way, associated with doing and knowing (Nicolini, 2011). While consulting with the tribal patient, the physician becomes aware of social constructions and representations of the disease, in relation to the life world of the community. If the physician were to fail to understanding cultural norms, he or she might demand compliance with restrictive clinical prescriptions, but knowledge of the community and its norms enables the physician and counsellors to initiate a dialogue to explain the embodied difficulties instead. The translation of the clinical meaning helps reduce the distance between the clinic and community to reflect local meaning systems. Such awareness is critical to expanding organizational knowledge and thus limit the risks for pregnant women with sickle cell diagnoses. It also provides clinical feedback to information systems.

In summary, the range of technological entwinement, from audio-visual aids to registering visitors and reminding them about visits, construct ample opportunities for interactions and participation with the community. Responses by patients and their relatives provide vital knowledge opportunities. Through these interactive opportunities, the VSO initiates a generative knowledge creation infrastructure. Without such structures, the VSO likely would struggle to understand the social-clinical experiences of the community, which are critical, considering the genetic and environmentally governed symptoms of sickle cell.

Technology ensures that the interaction does not subordinate the patients' experience. The technological artefact also encourages interactional parity and enables the VSO to relocate the clinical valence to the community. Table 3 summarizes these sub-practices.

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Vignette III: From Care to Creating Field-Level Evidence

Interactions during patient visits and counselling practices create heterogeneous pools of information about each individual's clinical path. Knowledge implies an ability to differentiate or draw distinctions (Tsoukas and Vladimirou, 2001), which is constantly challenged by diverse information in practice. Counsellors and physicians encounter a range of clinical and social realities, which likely increase confusion about clinical and operational work, but they also contribute fundamentally to technology-mediated knowledge creation at two levels: individual care procedures at the organizational level and evidence creation at the field level.

At the individual level, technology can resolve temporal losses of information across the care continuum (Appendix B). The historical details of a genetic disorder are critical inputs for understanding how to deal with an emergent clinical condition, so according to a physician, "it is important to know multiple clinical indicators from past. The severity of sickle vary among individuals, and two people with same symptoms may be different in severity of sickle. Knowing the history is very important. Unless we know the past we may miss the gravity in present." Since 2015, VSO has created over 1500 individual registers, reflecting the history of each patient with specific clinical presentations. This reservoir of digital registers enables it to offer clinical interventions that reflect the individual's history; it also constitutes a significant source of knowledge. Sickle cell presentations, clinically correlated with the community's genotype and environmental factors, demand organizational action, which is possible only if evidence about the history of a patient or a pool of patients is available, along with typical social-environmental factors. This significant knowledge practice creates community-level benchmarks, hitherto unknown in the local field. As one doctor elaborates:

> We observed that Hb [haemoglobin] level in some patients was not increasing and it continue to remain at low level … say 8-8.5! we looked into our data and find there are individuals with this type of condition [anaemic] …we spoke to an expert, and he suggested to get thalassemia diagnosed in such subgroup.

That is, the technology served as a repository of true information that provided vital clues to the care. The VSO has grown more "attentive to such persistently low haemoglobin patients" and established a separate clinical path for them. Linking technological inputs, even from prior paper-based records, to the information system can produce novel insights for benchmarking community parameters for sickle cell care.

At the field level, the ICT also enables the VSO to contribute to knowledge creation by producing evidence. For example, sickle cell severely affects maternal health and outcomes, but the extent and community-level characteristics were not known. With a post hoc longitudinal study, the VSO sought to learn how sickle cell status affects maternal health (Desai et al., 2017), which revealed higher mortality, greater clinical vulnerability to parameters such as anaemia, low birth weights, and need for transfusions in tribal woman. These novel findings and care framework (Saxena et al., 2017) reflect the creation of field-level evidence and knowledge in the organization, which constitutes an important, technologically enabled practice that distinguishes this knowledge practice. Identifying individuals in a pool, keeping a track of their clinical history, and exploring alternatives together create gradients of information, with the aid of technological interventions.

Prior literature often anticipates that knowledge management practices are internally oriented, to better the organizational service delivery and value creation (Srivastava and

Shainesh, 2015). In addition, the VSO engages with tribal communities at two levels, mediated by technology, which bridges fragmented interfaces and paves the way to create situated practices in more social-clinical-technical ways. By combining the social with the technical, the VSO generates multiple clinical cues for the community, enabling them to moderate their life routines and improve their quality of life. By creating multiple, graduated care benchmarks, it also generates evidence to inform clinical, scientific, and healthcare institutions. Figure 1 depicts the resulting framework of the role of technological entwinement in knowledge practices by VSO.

Conceptual Model and Implications

This study shows that ICT can be a source of generative knowledge structures that create multiple specialized practices within an organization. These practices initiate knowledge creation during interactions of expert clinicians or frontline counsellors with tribal patients; they also lead to progressive specializations and EBM, as the conceptual model in Figure 1 indicates. Knowledge creation related to sickle cell care practices also represents an opportunity to instantiate how ICT intertwines in this rich socio-cultural context. Therefore, this study contributes to literature (Barley et al., 2018; Carlile, 2002; 2004, Nicolini et al., 2008, Sheffield, 2008, Srivastava and Shainesh, 2015) that details knowledge management practices, by identifying interactions as critical input to an integrative system that can support new, context-bound evidence in healthcare.

Figure 1 indicates that, for the care of genetic and rare disorders, different actors adopt different truths, so it becomes necessary to find a common ground during interactions. Patients focus on their social experiences of pain, and allied practices; the physician is more concerned with clinical complications and depends on patients and their families to understand individual and epidemiologic forms of the disease and its hereditary and environmental influences. These differences call for interpretive mediation. The counsellor, who is from the tribal community, represents a third node who recognizes the different versions of sickle cell and deploys discursive interpretive and interactional skills to help bridge the divide between the clinician and the patient. In the outdoor clinic's interactional space, patients come to comprehend the meaning of pain and sickle cell, while the physician gets closer to the community. Technological interventions, such as videos and a Tablet, lead to greater interactional proximity and a partial integration of fragmented knowledge. The interventions include patient registration, recording patient history, and follow-up management, along with registering medical progress.

These ICT thus establish the initial common ground and structure interactions to prioritize *knowing the community*, beyond medico-clinical experiences. Such practices in knowing entail organizing explicitly situated, tacit interactions that previously had been distributed and localized among actors (Figure 1). Such fragmentation across actors, often with different socio-linguistic origins, can represent a barrier, unless a common technological and tacit element combines these different contexts. The counsellor, along with the clinician (Vignette I), instead builds bridges by listening, exchanging, translating, and interpreting—not just, in one physician's words, "clinically administering their lives." These practices initiate knowledge creation in the organization, represented through explicit overlaps among the expert, the counsellor, and the tribal community during rich interactional practices. The technology creates an initial artefact, as represented by the digital entries of history that capture clinical and social realities to serve as a primer that also can be extended in the future.

Over time and multiple interactions, these practices enrich the organization's knowledge pool, as is apparent in patients' increased awareness of clinical signals, which help them prevent severe consequences; the enhanced familiarity of the counsellor with the clinical presentations exhibited by each patient; and the physicians' experiences of potential clinical complexity and socio-environmental influences. Accordingly, the ICT used by the VSO builds on initial knowledge structures, and its situated practices are influenced by tacit knowledge. These practices offer the possibilities of new social and clinical facets, dynamically captured by evolving technological artefacts. Many patients request discharges or visit traditional healers, so these requests now are included in the technological artefact, which represents an acknowledgment of clinical–cultural confluence in knowledge practices. Such instances, integrated in the information system, allow it to intermediate a discursive social practice and indicate a granular possibility for creating new evidence.

Finally, technology helps extend possibilities for knowledge integration and specialization in the field. The evolving body of knowledge paves the way for progressive clinical specializations in VSO, supported by its own clinical research, as exemplified by the recent study, using longitudinal data about the clinical presentations of pregnant women (Desai et al., 2017). Such research outcomes provide collective evidence about maternal care needs and also prime the organization to pursue greater clinical engagement with sickle cell mothers. In turn, a team of gynaecologists, administrators, nurses, and counsellors collectively seek to commit to new benchmarks of care. Other organizations similarly might create avenues for specialization of care if they expand the systems beyond a specific program management tool. Reflecting the evolution in care practices since 2011, a senior doctor noted, regarding the use of haemoglobin levels as a benchmark, that “everyone knows the history and new standards.… [We] aggressively maintain high level of haemoglobin among sickle cell mothers.”

---------------INSERT FIGURE 1 ABOUT HERE---------------

As Figure 1 shows, these specializations provide clinical evidence and create opportunities to develop EBM practices for the field coupled with knowledge generation potential of ICT. That is, ICT in the VSO extends beyond program management tools to include evidence creation efforts. The trajectory of knowledge in this case moves from a fragmented knowledge pool to an integrated knowledge system that progressively supports greater specialization and context-specific evidence creation. In practice, it co-exists with bundles of tacit practices to support sickle cell care.

Conclusions

This study explores the entwinement of ICT-based practices for managing a rare genetic disorder that severely affects tribal communities in India. It highlights some significant knowledge practices. Organizational efforts to engage with locally embedded tribal communities in clinical spaces often face challenges, but as this study shows, they can be opportunities for knowledge creation. In practice, clinicians and counsellors engage with the social and embodied experiences of the community to initiate care processes, centred around the community. Three technology-mediated knowledge practices arise from the findings. First, *knowing the community* creates a knowledge structure for technology and human actors; it involves listening, exchanging, translating, and interpreting sickle cell to prepare a common ground for actors to engage further. The technological entwinements with human actors can become of a source of generative knowledge in subsequent interactions, both proximally and distally. Tacit practice dimension are critical to practice based knowledge in organizing care. Second, interactions in the clinic through the practice of *increasing and persistent interactional engagement* enable service delivery on one hand and creating context specific knowledge in longitudinal manner. Third, the organization develops specialization and creates evidence based medicine knowledge sets by *constructing individual and collective socio-clinical histories,* intermediated by arrays of ICT entwinements. These practices together create context specific knowledge about a hereditary disorder.

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Table 1. Data Structure

Source	**Details and Purpose**
Observation	
- The outdoor patient consulting activity	Shadowing visiting patient in the process of outdoor consulting and diagnosis day routine (Appendix A for detail). To understand the important interaction points and their role in education, narration, and self-awareness of the patient with regard to the processes.
- Counsellor's technology mediated interaction in clinic	Counsellor's routine with technology and human actors presented a complex interplay of communication and clinical practice. To analyze the pattern of technology enablement in communication and clinical practice in work practices.
- Counsellor's routine to contact patients in community	Shadowing counsellor to her routine work day beyond consulting day activity. Focus was on her reminders to the patients and their family about visit to clinic over a mobile call. Understanding the nature of distal communication pattern over mobile phone and how the reminder constitutes the recap of clinical view of VSO. Difficulties in persuasion and practices to overcome the life world concerns of the patients.
Interviews	
Doctor (3),	Understanding their interactive engagement and constructions of sickle cell care. With doctors, focus was on understanding the clinical and communicative challenges in delivery of care.
Counsellor (2),	With counsellors, focus was also on understanding their acquaintance with technology and its role in their routine performance.
Patients including family members (10)	With patients, focus was to understand their life experiences with sickle cell and how they learn to negotiate its complications.
Archival Material Technology app - Tablet,	Technological feature of the Tablet and its interactive features with their evolution was main focus. How these features relate to complexities of clinical and social feature of community.
Published papers	Scientific publications in journal and conference papers were studied in detail along with routine academic meeting. They point towards a longitudinal emphasis on understanding the pattern in sickle cell care, both at individual and collective level.

Table 2: Technology Mediated Interactions in Outdoor Patient Clinic

Interactional detail	**Means (Object/technological artefact)**	**End outcome**
Reminder call for visiting clinic on scheduled time	Mobile phone and Tablet App reminder	Interacting distally with the patients and their family to schedule next visit and enquires the sickle cell experience and signals in between visits
Motivating family members of patients/carriers for sickle cell screening	Diagnostic tools and entry in family register	Screening the spread of disease and extent of transmission with in the family and community on a larger level
Showing video in group	Audio-visual devices like television, pen-drive, player	Educating and translating the various social and clinical dimension of sickle cell. It signal through visual artefacts about the genetic nature of sickle; demystifying the local constructions and cultural practices; reason of pain among others.
Enrollment of people for Outpatient clinic using Tablet and paper file	Tablet App – a new page created and details are copied to paper file in parallel	Creating new folders/pages in the consulting history
Invoking memory of past pain episode	New page to register the intermittent pain account	Bringing memory from past into current conversation to link past embodied experiences. Such linkage in time generate a rich clinical account of sickle.
Elaborate the meaning of diagnostic parameters	Entering the diagnostic report and correlating with past data to create a digital temporal register	Translating the meaning of current diagnostic parameters and creating knowledge path to attend the symptoms. Linking the pain with the season sensitize the environmental linkage of sickle cell discomfort.
Exchanging phone numbers	File and phone	Reducing distance by enabling continuous connect between community and clinic
Collective consulting interactions	Heterogeneous assemblage of technology, expertise, community	Creating a collective environment of learning and solidarity to help through clinical cooperation

Table 3. Summary of Identified Practices from Vignette I & II

1. Practices in new registration		
Technology Interface	**Interactional details**	**Interactional Outcome**
Registering details of history in Tab (Artefact)	Asking about personal history of experience; geographic location of their work and life; family history of pain experiences and practices. details of paternal and maternal side geographies.	Social Knowing by registering the demographic, personal and social accounts like location, family history, work sphere
Listening and recording history of pain and family condition (Artefact)	Asking about activities during the pain; Nature of pain, site and intensity of the pain experience, remedies of pain.	Knowing the clinically embodied historical sickle experience
Showing the Video and animation on mobile (audio-visual)	Explaining the meaning of sickle as genetic condition; incurable and persistent; yet manageable with learning.	Interpreting and visually facilitating to convey the multiple meaning of sickle
Recording the diagnostic details of the visit including hemoglobin level, HPLC test to determine the extent of sickling (Diagnostic technologies interface with Tablet features)	Diagnostic explanation of the tests reflecting the well-being in the present	Translating the technical meaning to one of a personal meaning of wellness
2. Practices in reminder and follow up		
Technological Interface	**Interactional Details**	**Knowledge generation outcome**
App reminder feature provide list of the patients and subsequently the counsellor calls to the contact number and engages in long conversation. Counsellor enter details after the call (Artefact as well as paper entry with codes)	Reminding the family and patients about impending visit schedule in future and explaining the purpose to the person on other side. For example, the frequency of visit is per month in case of the pregnant woman and for other type of patients, once in three months. Supplemented by reminding the dosage and availability of medicine.	Extent of persuasion required to ensure the follow up visit (Intensive and persistent follow up effort). Determining the extent of clinical and communicative support required to avert crisis like situation at home. Educating to identify the severity of embodied symptom to self-manage the moderate pain.
Entering reason of delay in paper register	Exploring the reason for delay in coming to the clinic on scheduled time, if reported	Generating knowledge about Socio-demographic-biologic determinants of follow up management
Registering the details of experiences after last visit in a separate register.	Asking pain relapse after last visit to VSO, and emergent visit to any other healthcare facility due to pain. Reminding the medicine dosage and asking about the availability of medicine at home.	Knowledge about intermittent hospitalization and severity of sickle cell crisis frequency.

Appendix A. Flow of the Outpatient Consulting and Use of Communication and Technology

Enrollment after arrival of the patients in morning

Counsellor enter personal details such as name, father's/Husband's name, detailed geographic location, contact number in the sickle cell App. Important additions are taking historical description like first date of registration which signify formal care seeking

Collective viewing of the sickle cell videos by the group of patients and their family

The videos portray number of issues in sickle cell such explaining the clinical meaning of sickle, its biological-genetic basis, distribution in communities, types, symptoms, crisis, and display animation of blood particle shape and movement etc.

Measurement of vital parameters and recording the clinical history by the counsellor

Individual monitoring of vital parameters and counsellor take history after last visit. This includes asking detail of crisis like event since last visit/year, number of hospitalizations, required blood transfusion among others.

Referral for diagnosis screening by the counsellor

This referral is significant addition to the counsellor routine work as she can refer for diagnostic screening on her own enabled by technological tracking of past.

For hemoglobin level measurement to know the present anemic condition, measurement of sickling condition by high performance liquid chromatography (HPLC) screening, liver profile showing effect of medications among other.

After diagnosis, counsellor explains the meaning of the reports

Counsellor translate the meaning of the hemoglobin levels, extent of sickling shown as peaks in the HPLC records, and attempts to link with the experience of pain and discomfort. She often reminds the signals to be attended by the patients.

Consulting and physical examination by the clinician. Counsellor is present during the consulting and examination.

Clinician ask the various question regarding physical activity level of the patients, elaborate pain episode correlation with climatic condition like rain etc., stress understanding symptoms and counsel on marriage relating queries of the parents/guardian among others. Finally, the medicines are prescribed.

Counsellor explain the dosage and remind about the next scheduled visit

The counsellor explains the dosage to the patients and the accompanying family members. This is a very important step in the engagement. The medicine is referred by their color and linked to symptom like fever, pain, crisis experience among others. The counsellor reasserts the talk happened throughout the day and reminds for next visit date.

Appendix B.

Vignette 1:

Missing the paper file and follow up: Significance of technology as repository of information to facilitate care in lost follow up.

A twenty-one year old female patient arrives on outdoor patient clinic day of VSO. Upon repeatedly requesting to show her file, she informs to the counsellor that she is 'without any file'. VSO recognizes that paper files has their own importance as it can become very useful 'if patients need emergency care at any other center or in case of referrals to higher center' as stressed by the clinician. However, without any delay, the counsellor engages with the patient and empathetically asks about her present condition. The purpose is to identify any discomfort experiences, such as pain or fever, or something else that must be attended immediately. The counsellor identifies by 'little response from the patient' that patient needs to be 'counselled more'. This quick evaluation of counsellor is an important tacit practice. She understands that she needs to interact and train her further so that they can express their problems better. A The clinician also acknowledged that it is important since significance of past history in hereditary disorders is critical and VSO cannot administer medical intervention only by interacting to the patient on the day of the visit.

Keeping the digital history of patients is important task to the organizational practice. The retrieval of information from systems revealed a recent 'loss to follow up' as the patient had missed two scheduled visits in last two months. Due to change in her location from address mentioned in the registration details, VSO could not reach to her. She told that she was living with her mother due to some family reasons. On that day too, she had travelled 55 kilometers, further indicate value of follow up communication and maintaining address of in-laws as well as maternal place. Clinically, it was found that she required emergent medication of hydroxyurea and her vaccination schedules were also imminent. The use of digital registers is extremely critical in keeping the track of clinical journey, in care delivery and evidence creation in care of sickle cell to pregnant women.

Vignette 2:

Excerpts from the observation of meeting and research paper seminar revealing insight about alternative diagnosis application to screen sickle cell in new born:

As a commitment to understand the severity of sickle cell distribution in tribal population in its geography, VSO regularly engages with all relevant stakeholders in field of medicine. In this meeting, the clinician emphasizes screening newborn child for sickle cell disease. Since neonate mortality is very high, thus highlighting the critical importance of an early diagnosis, he elaborates the 'unknown' in the pattern of sickle cell in neonate. VSO partnered with other organization to develop a novel device which provides more accurate and speedy diagnostic of new born. Based on a rapid test, of a cohort of over 200 children at VSO, an initial estimation revealed that 'early diagnosis can improve mortality rates by 70%'. Other centers who partnered in this study combined their resultant insight. This technologically pooling of evidence facilitated value of newborn screening. At present other longitudinal study is ongoing, and VSO believes that through careful observations, data collection, communication, follow up, and clinical management could provide new insight to manage sickle cell better. This highlights the role of introducing new ICT technologies in clinical space focusing on data management and analysis can aid the preparing clinical history of early diagnosed neonates (Practice III reported in the study) as they advance in their life.

Endnote

[i] [1]Counsellors: Counselling is essential component of routine care delivery at VSO. It recognizes that the marginalized populations' concepts of disease and health create a barrier to their access to healthcare. Most of the counsellors themselves belong to tribal community and in routine communicate to explain medical processes in vernacular form and calibrate the communication to the needs of tribal patients and their families.

[ii] VSO: Found in 1980 to serve poorest of poor with a mission in remote tribal area. VSO provides Gynecologic, Obstetric, Pediatric, Ophthalmologic and General Medicine services apart from sickle cell care. More than 150,000 patients visit outdoor departments with over 20,000 indoor admissions. It has received award and recognition from WHO, USAID, UNESCO and several other foundation and organizations including government for its services to rural tribal population.

[iii] Vaso-occlusive crisis: commonly referred as underlying cause of sickle cell pain and arises due obstruction of blood flow due to sickle shaped blood cells.

[iv] Ischemic injury: is restriction of blood supply, and hence oxygen, to tissues leading to dysfunction of tissues

[v] [5]Video: A twenty minute play showing the pain of sickle cell and the response of a tribal family. VSO routine employ audio-visual aids in elaborating clinical and social dimension of important health challenges to the community.

[vi] HPLC: Acronym for high-performance liquid chromatography method of sickle cell test. This is used to identify the type of hemoglobin in blood.