

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

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Abstract

Purpose – This paper aims to examine the role of information and communication technology (ICT) in the knowledge creation practices adopted by a health care organization. The organization is delivering care to patients of a genetic disorder, called the sickle cell, in tribal communities. The paper identifies how ICT intermediates knowledge creation practices across the organizational boundaries wherein tribal patients, front-line counselors and expert physicians interact, which then produces context-specific, evidence-based medicine (EBM).

Design/methodology/approach – The knowledge-in-practice approach is adopted to conduct an ethnographic study of sickle cell care practices in a non-profit health care organization in Western India. The analysis focuses on ICT-mediated interactional practices among the physicians, front-line counselors, tribal patients and their families, for more than a year-long observation. These are supplemented with informal and formal interviews, archival records and vignettes based on several episodes to explicate the key knowledge creation practices.

Findings – Technology-mediated informative interactions at organizational boundaries can bridge socio-linguistic and interpretive barriers between actors, while also providing a generative structure that leads to the creation of longitudinal clinical evidence about a rare genetic disorder. Three specific ICT-entwined knowledge creation practices emerge, namely, knowing the community, increasing interactional engagement and constructing gradients of socio-clinical history. These practices generate organization-wide knowledge about the social and clinical dimensions of the genetic disorder. The findings are presented through vignettes and a novel conceptual framework.

Research limitations/implications – This study identifies various useful knowledge creation practices in health care delivery for resource-constrained emerging economy contexts. Further, the study suggests that the involvement of local front-line actors and ICT can become important resources in the delivery of health care in these settings.

Originality/value – A novel framework is developed which demonstrates knowledge creation at organizational boundaries wherein the actors use ICT-based practices for effective delivery of health care. The proposed framework may be used by health care organizations in similar contexts providing care to marginalized communities.

Keywords Knowledge creation, Tribal community, Health care in emerging economies, ICT based practices, Sickle cell, Front-line counselors

Paper type Research paper

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Introduction

A healthy society is paramount to all kinds of human progress. The global pandemic due to the spread of COVID-19 has once again brought the issue of a healthy society to the forefront of all kinds of debates. Even prior to COVID-19 pandemic, the sustainable development goals (SDG) of the United Nations reflected deeper concerns for achieving equitable world through solving issues of health, well-being, environmental damages and social inequalities (George *et al.*, 2016). In particular, SDG 3 sets an agenda of action to ensure *healthy lives and promote*

well-being for all at all ages (UN Security General, 2019). This is indeed an ambitious goal requiring unprecedented efforts, particularly in countries that are resource-starved in health care infrastructure. While developed countries have established advanced infrastructure for knowledge management in health care, emerging economies lack in this domain. To that end, this paper sets out to understand the knowledge creation practices in the care of sickle cell disorder, which remains one of the most neglected genetic disorder having severe implications for maternal, newborn and child health in native communities globally (McGann *et al.*, 2016; Singh *et al.*, 2019; Ware, 2013). Health care systems, which provide care for sickle cell disorder in developed economies, have emphasized the role of information and communication technology (ICT) based practices for an effective transition between different care services within the hospital premise (Frost *et al.*, 2016). However, in emerging economies, this disorder continues to prevail among the marginal communities where institutional provisions of care remain constrained due to socio-economic, cultural and clinical factors (High-Level Committee Report, 2014).

A high prevalence rate of sickle cell among the tribal population of India and Africa accentuates the vulnerability of the marginalized groups (Colah *et al.*, 2015; Hockham *et al.*, 2018; Saxena *et al.*, 2017; WHO, 2006). In the tribal population, sickle cell presents more nuanced intersectionality of gender, life stage, economic condition and cultural context, all of which may pose severe challenges to achieving SDG #3 of the United Nations. The diverse representations of communities' history, individuals' subjective experiences of sickle cell disorder, linguistic and dialogical differences between the clinical and socio-cultural contexts pose serious challenges to the creation of organization knowledge structures (Basu, 2000; High-level committee report, 2014). To overcome such challenges, we submit that an effective sickle cell care program should extend beyond clinical and socio-cultural boundaries to enable organizational knowledge creation through ICT interactional interventions at all the stages of care. Thus, in this paper, we examine *How does ICT enables and intermediate knowledge creation practices at the boundaries of the organizations, and How do ICT enabled interactions among actors of community and clinic to produce context-specific evidence for the delivery of health care?*

We situate our study in a non-profit health care organization, delivering sickle cell care to tribal communities to understand knowledge creation practices. We use Nonaka's (1994, pp. 23-25) proposition as the theoretical anchor, which suggests that knowledge creation necessitates consideration for organizational boundaries as a source of *tacit* knowledge. Further, knowledge creation requires continuous dialogue to create "*Ba*," which refers to a physical, virtual and or mental form of a shared space for emerging relationships and experiences, thus providing an essential platform for knowledge creation (Nonaka and Konno, 1998, p. 40). Organizational knowledge structures emerge from:

- individual-level factors including social resources, patterns of conduct and communication;
- context; and
- knowledge creation process (Sheffield, 2008; Tsoukas and Vladimirou, 2001; Von Krogh *et al.*, 2012).

Integrating the ICT resources and knowledge assets among clinical and non-clinical actors would be necessary for effective health care delivery in emerging economies (Srivastava and Shainesh, 2015). Accordingly, we argue that organizations can leverage ICT to bridge fragmented knowledge of all actors (Bruni and Teli, 2007) such as expert physicians, front-line counselors, nurses, tribal patients and the community.

We do an ethnographic study [1] in a non-profit health care organization situated in Western India, which we refer to anonymously as the Voluntary Service Organization (VSO) [2]. VSO has been providing sickle cell care to the tribal population since 2011. Our study

reveals that technology-mediated interactions among the actors at organizational boundaries provide critical avenues capturing tacit knowledge. We develop an integrative framework that takes us toward a more comprehensive understanding of various levels of ICT mediated practices for the terminal need for knowledge creation in sickle cell care. This research leverages the rich ethnographic practices (Watson, 2011) such as prolonged observations, shadowing of actors, interviews and readings of archival records.

Our analyzes reveal that ICT based interactions among actors at organizational boundaries can be represented by three knowledge creation practices. First, practice about *knowing the community* involves listening, exchanging, translating and interpreting the various meanings of the social and clinical dimensions of the sickle cell disorder. With this knowledge, the VSO could bridge interactional and interpretive divides among the organizational actors and the tribal community. Moreover, by deploying such micro-practices, the technology-supported exchanges create a shared space to bridge the wedge between the clinic and tribal patients. Second, *increasing interactional engagement* explicates how repetitive visits to the clinic by patients and families, create knowledge structures which build on the common ground prepared among the actors. While the technological elements increasingly codify the explicit dimensions, the tacit dimensions create situated knowledge-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 this population cohort. This specialization in clinical care leads to the creation of a pool of registers reflecting personal and community-specific benchmarks which constitute evidence-based medicine (EBM), beyond organizational boundaries.

This study makes several important contributions. First, this study reveals that ICT intermediates knowledge creation at the intersections of clinical and socio-cultural complexities, which can help in generating knowledge structures. Second, in the delivery of care, actors (particularly the front-line counselors) create a shared space that brings community-specific features to create organizational knowledge. Specifically, technology entwined interactions help transform these front-line counselors as knowledge workers who record tacit information for the knowledge registers of the organization. While the first two elements are critical for the creation of internal organizational knowledge, the third practice could enable organizations to create knowledge for the larger field beyond its boundaries. In medical practice, this signifies the importance of contextual socio-cultural evidence (Serjeant, 2016), which is highly relevant for various similar institutions serving marginal communities in emerging economies.

In the next section, we present a situational report on sickle cell disorder. This is followed by the theoretical anchoring of the paper, which focuses on knowledge creation at organizational boundaries and the role of ICT based practices in the health care sector. We discuss the ethnographic methods in the subsequent section, and then present the findings in a series of vignettes describing patient and front-line counselor interactions. Finally, we put forth a conceptual framework demonstrating the role of ICT in knowledge creation practices and discuss the theoretical and practical implications of our research.

Sickle cell disease

Sickle cell is a genetic blood disorder, clinically referred to as hemoglobinopathies, in which the red blood cell particles become hardened and brittle, deforming into a sickle shape, such that they do not last as long as normal red blood cells. It results in persistent anemic condition throughout the life of an affected individual and often results in higher mortality with clinical complications such as vaso-occlusive crises [3] and ischemic injury [4] (Nimgaonkar *et al.*, 2014). Across the globe, more than 250 million people suffer from the sickle cell (Hockham *et al.*, 2018; WHO, 2006). The disease affects even newborns; over 3,00,000 neonates are affected with sickle cell every year (Brousse *et al.*, 2014), of which 80% do not survive beyond five years of age (Rees and Brousse, 2016). This disease is

distributed globally, including in America and Europe, but it is highly prevalent in marginal native communities of Africa and India (Ballas, 2001; Piel *et al.*, 2013; Rees and Brousse, 2016; WHO, 2006). Piel *et al.* (2013) project that the global burden of sickle cell is likely to increase, necessitating more attention toward its local variations that may require locally appropriate models of care (Serjeant, 2016).

In India, sickle cell reportedly affects a sizeable population, and a significant number of sickle cell disease patients belong to the tribal population (Saxena *et al.*, 2017). This tribal population, commonly called as *Adivasis* in India, constitute 8% of India's population (100 million approximately), is subjected to special provisions for their educational, economic and protective interests. However, many still suffer development gaps because of malnutrition and anemia (High-Level Committee Report, 2014). To date, there is no generalized protocol regarding the epidemic and clinical forms of sickle cell in local tribal communities also due to their social history and environmental determinants (Serjeant, 2016; Tewari *et al.*, 2015). Moreover, sickle cell manifests in women, children and adolescents differently and many sufferers prefer to seek care from alternate healers rather than expert physicians. However, we lack systematic evidence reflecting longitudinal studies of life events experienced by tribal patients diagnosed with sickle cell in India (Nimgaonkar *et al.*, 2014; Saxena *et al.*, 2017).

All these factors highlight an urgent need for understanding an organizational knowledge management approach, and VSO provides an ideal context to explore such practices associated with the management of sickle cell disease, evidence-based longitudinal care in cohorts of patients. VSO is one of the few organizations in India, which deploys information and communication technologies while screening, providing outpatient care and indoor admission and maintaining extensive communicative engagements to the sickle cell families and the local community. Accordingly, this study explores the ICT based practices adopted by VSO, which lead to organizational-wide knowledge creation and construction of clinical evidence for a larger field of care providers.

Theoretical background: Knowledge creation at organization boundaries

Knowledge creation is defined as “the generation, development, implementation and exploitation of new ideas” (Mitchell and Boyle, 2010, p. 70). Knowledge creation requires multiple interactions and collaborations among actors. This process is contingent on cross-over interactions beyond the formal boundaries of an organization as it determines the access to resources and actors (Nonaka, 1994; Nuruzzaman *et al.*, 2019; Schotter *et al.*, 2017). In the case of sickle cell, however, such cross-over interactions while accessing the health care institutions may be difficult due to deeper wedge on account of linguistic, social, economic, cultural and infrastructural barriers (Colah *et al.*, 2015). Highlighting the importance of dialogue among actors as an essential prerequisite, Nonaka (1994) argues that such interactions may facilitate knowledge creation. In what he referred as the “narrow boundary” of the organization, Nonaka (1994, p. 23) proposed that deliberate interaction with the external environment in the form of customers, suppliers and communities may become significant sources for the creation of organizational knowledge (Fayard, 2003; Nonaka *et al.*, 1996; Nonaka and Nishiguchi, 2001; Pedersen *et al.*, 2019; Schotter *et al.*, 2017). Further, the concept of “Ba” added a notion of shared space that helps in organizational knowledge creation through emerging relationships (Nonaka and Konno, 1998).

Conversion between tacit and explicit dimensions may enable knowledge creation (Nonaka, 1994; Nonaka and Konno, 1998). In this study, we explore how ICT enabled exchanges among clinical professionals and the tribal community shape the knowledge structures of the organization. We submit that the subjective aspects of disease along with social and community-based experiences would constitute tacit dimensions. ICT based practices may enable conversions of social, biographical and community-based facts leading to clinical knowledge and actions. Until now, the literature has investigated a limited role of ICT in

health care facilities in emerging economies. Empirical evidence suggests that ICT based practices have strengthened health care delivery by enhancing communication and emergency responses in maternal care (Chib, 2010); preventing of diseases such as HIV/AIDS by making large scale coalitions (Passerini and Wu, 2008); virtually connecting village doctors to formal doctors (Khan *et al.*, 2015); and designing better health care interventions (DeSouza *et al.*, 2014; Modi *et al.*, 2019). In a recent study, Singh *et al.* (2018) find that Web 2.0 methods such as blogs and social networking sites have provided better access to knowledge and increased knowledge sharing among health care professionals in India. While the above research has generated considerable insights, it remains confined in the professional boundaries of health care infrastructure. We submit that interactions with tribal communities having sickle cell experiences mobilize additional sources of tacitness which are rooted in their biographic-cultural-historical memory. We suggest that ICT based practices could provide opportunities for exchange between tribal population, suffering from the genetic disease of sickle cell and front-line workers in clinical settings leading to knowledge creation.

Prior studies that examine cross-functional teams (Carlile, 2002; Mitchell and Nicholas, 2006) or distributed systems (Lee and Cole, 2003) suggest that knowledge creation is a social process. As multiple social processes are embedded in the relationships of various actors, within and outside the organization (Liu and Meyer, 2018; Nonaka and Nishiguchi, 2001), we explore how the front-line counselors' practices, enabled by ICT systems, may integrate heterogeneously and dispersed external knowledge (Kraaijenbrink and Wijnhoven, 2008) to the organizational repertoire. In our context, the front-line counselors belong to the tribal community and may bring subjective experiences to the fore and narratively increase the possibility of developing an effective social architecture of knowledge transfer (Mitchell and Nicholas, 2006).

Technological resources facilitate collaborations and interactions (Passerini and Wu, 2008) by providing avenues for information recording, processing and communication among internal and external constituencies (Srivastava and Shainesh, 2015). Moving beyond translating tacit knowledge into explicit and standardized components (Nicolini *et al.*, 2008), ICT based systems can have generative roles (Leonardi, 2007) too, which may create multiple trajectories beyond new routines (Barley *et al.*, 2018). As an intriguing research area in the knowledge management domain (Gaur *et al.*, 2019), this study, therefore, seeks to understand how ICT based practices facilitate information integration at organizational boundaries (Venkitachalam and Busch, 2012). Based on the above, this study has two related research questions. First, we ask how does ICT enables and intermediates knowledge creation practices at the boundaries of the organizations and second, how do ICT enabled interactions among actors of community and clinic to produce context-specific evidence for delivery of health care?

Methods

The data collection involved various ethnographic practices such as observations, shadowing, interviews and archival study (Gaur and Kumar, 2018; Leonardi, 2007; Watson, 2011) in sickle cell care between 2016–2018, in association with VSO. The surrounding area where we conducted the study, is populated by heterogeneous, rural, tribal communities and the weekly outpatient clinic provided consulting to patients from three states of western India. Since 2011, VSO began intensive sickle cell program, and in 2015, introduced ICT based processes in the patient care.

The data collection effort focuses on two main goals. First, it aims to identify the practices that build 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 do in interactions (Duvivier *et al.*, 2019; Leonardi, 2007; Nicolini, 2007; Watson, 2011) as it reflects the meaning-making and order activities. Such methods have been used to study ICT based interactional patterns in health care 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), we focus on 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 (Leonardi, 2007). The outcomes obtained through their use might include initiating or registering patients for their outpatient visits, counseling, diagnoses, recording diagnostic parameters for experts to review and reminding patients of future visits. To complement this data, the authors also observed the sickle cell ward, which reveals intensive, complementary practices. These specific practices when mediated by ICT, are used in dynamically structuring the knowledge in this context.

Table 1 presents the details of data collection. The first author shadowed patients and front-line counselors on outpatient visit days (once in a week), shadowed the sickle cell front-line counselor during routine workdays, observed consultations and attended the research meetings. Detailed memos described the discursive episodes to reflect individual knowledge practices, as well as the interactions of the front-line counselor who made calls to patients or relatives before and after their visits to the clinic. We present these details in Appendix 1. The author team undertook informal and formal interviews with physicians, front-line counselors, patients and their relatives to elaborate on the practices. The analysis of the interactional pattern in an outpatient clinic, interview transcripts, published documents and archival

Table 1 Data structure

Source	Details and purpose
<i>Observation</i>	
<ul style="list-style-type: none"> The outdoor patient consulting activity 	<ul style="list-style-type: none"> Shadowing the visiting patient (MB) in the process of outdoor consulting and diagnosing the daily routine (Refer to Appendix 1 for detail) Understanding the important interaction points and their role in education, narration and self-awareness of the patient with regard to the processes
<ul style="list-style-type: none"> Frontline Counsellor's technology-mediated interaction in the clinic 	<ul style="list-style-type: none"> Understanding the frontline counselor's routine with technology and human actors presented a complex interplay between recording/maintaining information and clinical practice Analyzing the pattern of technology enablement in communication and clinical practices in their daily routine
<ul style="list-style-type: none"> Frontline Counsellor's routine to contact patients in a community 	<ul style="list-style-type: none"> Shadowing frontline counselor during her routine day at work beyond the consulting activities. The focus was on her reminders to the patients and their family about visiting the clinic through a mobile call Understanding the nature of communication patterns over a mobile phone and how the reminders constitute the recap of prior clinical visits at VSO Understanding the difficulties in persuasion and practices to overcome the concerns of the patients
<i>Interviews</i>	
Doctor (3)	Understanding their interactive engagement and constructions of sickle cell care <ul style="list-style-type: none"> With doctors, the focus was on understanding the clinical and communicative challenges in delivery of care
Frontline Counsellor (2)	<ul style="list-style-type: none"> With frontline counselors, the focus was on understanding their acquaintance with technology and its role in their routine performance
Patients including family members (10)	<ul style="list-style-type: none"> With patients, the focus was to understand their life experiences with sickle cells and how they learned to negotiate its complications. With family members, the focus was to comprehend their collective understanding of the disease and role of care
<i>Archival Material</i>	
Technology app – Tablet	<ul style="list-style-type: none"> Understanding the technological and interactive features available in the Tablet (Tab) Understanding how the inputs from frontline counselors result in modified versions of the application Understanding how these features relate to complexities of a clinical and social feature of the community
Published papers	<ul style="list-style-type: none"> Studying the scientific publications in journals and conference papers in detail along with routine academic meetings. These pointed toward a longitudinal emphasis on understanding the pattern in sickle cell care, both at an individual and collective level

materials helped reveal the knowledge practices of the organization. The interpretive data analysis (Nicolini, 2007; Schwartz-shea and Yanow, 2012) moved back and forth between emergent identified practices and the data. We also relied on 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, we had more than 100h of observations to understand the practices. Additionally, we recorded 25 episodes of shadowing patients during outpatient clinic days.

During visits, patients' interaction points were distributed during the day, for different collective and individual purposes (Appendix 1). 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 counseling sessions.

To present these findings, vignettes offer an effective mechanism, as is common in practice-based ethnographic studies exploring knowledge creation (Carlile, 2002). 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 front-line counselor'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 personal history. Additional vignettes are presented in Appendix 2.

Vignette I: Shadowing in an outpatient clinic

Scene 1

MB (acronym), 24-year male, reached the outdoor patient clinic at about 9:30 a.m. Past 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 a carrier of a sickle. As then, he has visited VSO at a prescheduled time; he received a call from *sister Roshni*, a front-line counselor at VSO, to remind him of his visit two days prior. *Sister Roshni* offers him a seat and asks him to hand over the file which he is carrying. The file contains a history of past visits with clinical and demographic details. She carefully reviews the last prescriptions and asks him to join a small group, sitting in the cubicle. The group watches a video [5] about sickle cell management in vernacular language in which the actors are staff members of VSO. MB exults:

I have seen this movie before. Here they show this to everyone. Look at him he is holding his ankle [pointing toward a visual about a person in pain]. It happens in the 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 the site of pain.

These audio-visual aids are viewed by 10-15 individuals including relatives of the patients in the front-line counselors' cubicle. The front-line counselor 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 (offline). The conversation goes as follows:

Front-line Counselor (FC): How are you, brother? Any pain in between [as the last visit]?

MB: Yes.

FC: When did it happen and where did you take help from?

MB: I was in the fields [agriculture], slowly I felt pain in my wrist and [point toward leg joints]. I could not work thereafter that day.

FC: Were you not taking medicine [vernacular language], the yellow-colored one?

MB: I was fine, could not see this [coming].

The counselor 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 was recorded in the paper file as well.

MB: I was feeling a bit of pain but thought it would go. My relatives had come, and they insisted on going accompanying 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 FC to assert it more, showed him his clinical history by turning pages of his paper file and asked him not to ignore it. She also urged him to visit any other clinic in an emergency with this file if a crisis were to arise. The front-line counselor wrote down the prescription of diagnosis for the visit and asked MB to proceed to the laboratory. Meanwhile, the number of patients registered increased to 30 by 10:30 a.m.

Scene 2

MB returns to the outdoor patient area and hands over the diagnostic reports to the counselor. The report contains an HPLC [6] record of the blood sample, liver profile and some more biochemical tests. She informed the first author that this patient's sickle cell ratio has stabilized, compared to last year's records, when he was hospitalized multiple times and indicating some improvement. She explained to the patient:

FC: Your report looks good, brother. However, do not ignore pain; otherwise, you will have to be admitted again. Whenever the 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 are sitting with their guardians, mostly women and the front-line counselor takes her seat to the right of a long table placed in the center of the room. The room is a makeshift consulting space, otherwise used for gynecological exams. The counselor 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 the file to locate day-wise diagnostic report]: Your condition seems fine but be careful [...] in this weather.

Usually, during the rainy season, the pain episodes are expected to rise in general and the counselor informs that during this season, VSO receives the maximum number of indoor admissions with a pain crisis:

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 the front-line counselor to remind everyone about the schedule of medicine].

FC: Past year, he was admitted 3–4 times, and underwent a blood transfusion.

MB: I visited the doctor in my village, and he gave me an injection.

The doctor asks him to come to a secluded chamber for examination. The doctor checks his abdomen and asks MB to check himself. This is done to educate the patient about an enlarged spleen, called splenomegaly, which coincides with discomfort. The doctor writes a prescription and asks him to talk to the front-line counselor again. In that interaction, the front-line counselor 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.

Findings: Insights from Vignettes

Vignette I: Actors interacting with information communication and technology

Table 2 provides a summary of how ICT mediates interactions in the outdoor patient clinic. To understand the role of ICT, we focus on actors' interactions and the influence of technology. Notably, in a situated manner, the video helped in educating the patients and their relatives about multiple dimensions of sickle cell disease. The content is delivered in the vernacular language, which helps connects with the patients. It depicts sickle cell symptoms and thereby translates clinical impacts into a local context. It highlights the hereditary nature of the 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 actors in the video are VSO's staff members, and this helps in reducing the community's fear of a clinic and depicts clinical consulting as a place shared by the physician, the front-line counselor, patients and families. The physical features and sequence of interactions in clinics are designed to reduce barriers between experts and the lay community. The preceding counseling 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."

By placing the moments of pain as central to the narrative, the interactions also rely on technology to discursively link an embodied experience to technical insights. Each patient's version of the intensity of pain, its location and the place – such as an agricultural field in the vignette, where they experience it, reflect their construction of the sickle cell, signifying the social-functional nature of the disease. Front-line counselors do not discount these mundane details of felt experiences but instead register the experiences diligently in the Tablet. Registering such episodes using a technological interface conveys the significance of the experiential accounts. The VSO's knowledge practices value such experiences as a 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 the community relates to the pain, we need to talk and listen. At times we struggle [. .] and asking them to

Table 2 Technology mediated interactions in the outdoor patient clinic

<i>Interactional detail</i>	<i>Means (object/technological artefact)</i>	<i>End outcome</i>
Reminder call for visiting the clinic on a scheduled time	Mobile phone and Tablet app reminders	Interacting with the patients and their family members on a phone call to schedule the next visit and enquiring about the sickle cell experiences in-between visits
Motivating family members of patients/carriers to undergo sickle cell screening	Diagnostic tools and entries in the registers maintained for patients' families	Screening the spread of disease and extent of transmission within the family and community on a larger level
Showing sickle cell awareness video in groups	Audio-visual devices such as television, pen-drive and video-player	Educating and translating the various social and clinical dimensions of sickle cell. It signals through visual artefacts about the genetic nature of sickle cell disorder; demystifying the local constructions and cultural practices and the reason for pain among others
Enrolling members from tribal communities for Outpatient clinic using Tablet and paper file	Tablet App – a new page created and details are copied to paper file simultaneously. The paper file records the frontline counselor's reflections and some quick information that she may need during patient interactions	Creating new folders/pages in the consulting history Detailed records of reflections and quick access to information
Invoking the memory of previous pain episodes	New page to register the intermittent pain account	Bringing memory from past into current conversation to link past embodied experiences. Such linkages in time generate a rich clinical account of sickle cell care
Elaborating the meaning of diagnostic parameters	Entries in the diagnostic report and correlating it with past data to create a digital temporal register	Translating the meaning of current diagnostic parameters and creating knowledge paths to attend the symptoms. Linking the pain with the season sensitizes the environmental linkage of the sickle cell discomfort
Exchanging phone numbers	Paper file and phone	Reducing distance by enabling continuous communication between community and clinic
Consulting in a collective manner	Heterogeneous assemblage of technology, expertise, community	Creating a collective environment of learning and solidarity to help through clinical cooperation

express is very important [...] the severity of pain, its effect, place and [...] economic hardships [...] all counts.

Then the physician and front-line counselors 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 front-line counselor's routine care provision. She draws on situated features to encourage patients to watch the video. Considering the diversity of patients, the film connects 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 front-line counselor digitally registers the account of pain episodes and other details between the visits and also notes it in the paper file. She is cognizant that each patient had received a reminder call from her which is recorded in her Tablet as well. Reminding and registering the patient creates a continuum of technologically assisted tasks; these reminders account for much of her workday 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 socio-economic difficulties [in the tribal community] [...] more

persuasion is required. Therefore, the reminder pop-up opens every day, the moment the counselor opens her Tablet. She cannot avoid it [...] now the follow-ups are more efficient than before [...] it is important as we cannot afford to compromise with the patient's health due to lack of follow-up.

Vignette II: Shadowing the frontline counselor

As noted, the counselor reminds patients about their scheduled visits in advance. She not only reminds patients about the next visits but also reconnects with patients and inquires 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 the field for kheti-majoori (labor work in the agricultural field) [...] then I have to speak to the Bhai (i.e., husband, relative, or guardian) [...] and they do not understand and often refuse to visit [...] I say that I will call in the evening again, once you reach home [...] I carry this [signaling to the phone] all the time [...].

Thus, reminders have social and clinical aims. They build regular social links and create a register of the community that the organization can use to prepare a plan for care. While most visits are scheduled three months in advance, physical distance, financial conditions, disease severity and emergent hospitalization might alter conventional patterns of care (Appendix 2). In this sense, technology helps the organization to connect with the community and also discursively increases the possibility of interactions in knowledge creation work. A physician elaborates:

We often see a particular patient who finds it difficult to visit even in three months. We provide support [...] like medicines for longer duration [...] and alert counselors 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 the 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 calls 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 personal clinical aspects creates a shared memory among participants such as when the front-line counselors invoke examples of patients by name, to cite their knowledge about the 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 front-line counselor. These new social realities inform the organization about how to recalibrate pathways of care to reflect spatially separated interactions. Third, front-line 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*. ICT at the boundary can bridge the divide between experts and the community to prepare the 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 Wenger, 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 understand cultural norms, he or she might demand compliance with restrictive clinical prescriptions, but knowledge of the community and its norms enables the physician and front-line counselors 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, provides ample opportunities for interactions at the clinic-community boundary. 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, frontline counselors would struggle to understand the social-clinical experiences of the community, which are critical, considering the genetic and environmentally governed symptoms of sickle cell. The technology ensures that the interaction does not subordinate the patients' experience. The technological artifact also encourages interactional parity and enables the VSO to relocate the clinical valence to the community and not toward the expertise of professionals. Table 3 summarizes these sub-practices.

Vignette III: from care to creating Field-Level evidence

Interactions during patient visits and counseling 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 continuously challenged by diverse information in practice. Front-line counselors and physicians encounter a range of clinical and social realities, which likely increase confusion about clinical and operational work. However, they also contribute fundamentally to technology-mediated knowledge creation at two levels, namely, 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 2). The historical details of a genetic disorder are critical inputs for understanding how to deal with an emergent clinical condition. As one physician stated:

It is important to know multiple clinical indicators from the past. The severity of sickle vary among individuals and also during transition phases in life, and even two people with the same symptoms may be different in the severity of sickle. Knowing the history is very important. Unless we know the past, we may miss the gravity is present.

Since 2015, VSO has created over 1,500 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, along with typical social-environmental factors, is available. This significant knowledge practice creates community-level benchmarks, hitherto unknown in the local field. As one doctor elaborates:

Table 3 Summary of identified practices from Vignettes I and II

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

We observed that Hb [hemoglobin] level in some patients was not increasing and it continue to remain at a low level [...] say 8–8.5! we looked into our data and find there are individuals with this type of condition [anemic] [...] 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 hemoglobin 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, 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 anemia, low birth weights and need for transfusions in the tribal woman. These novel findings and care framework (Saxena *et al.*, 2017) reflect the creation

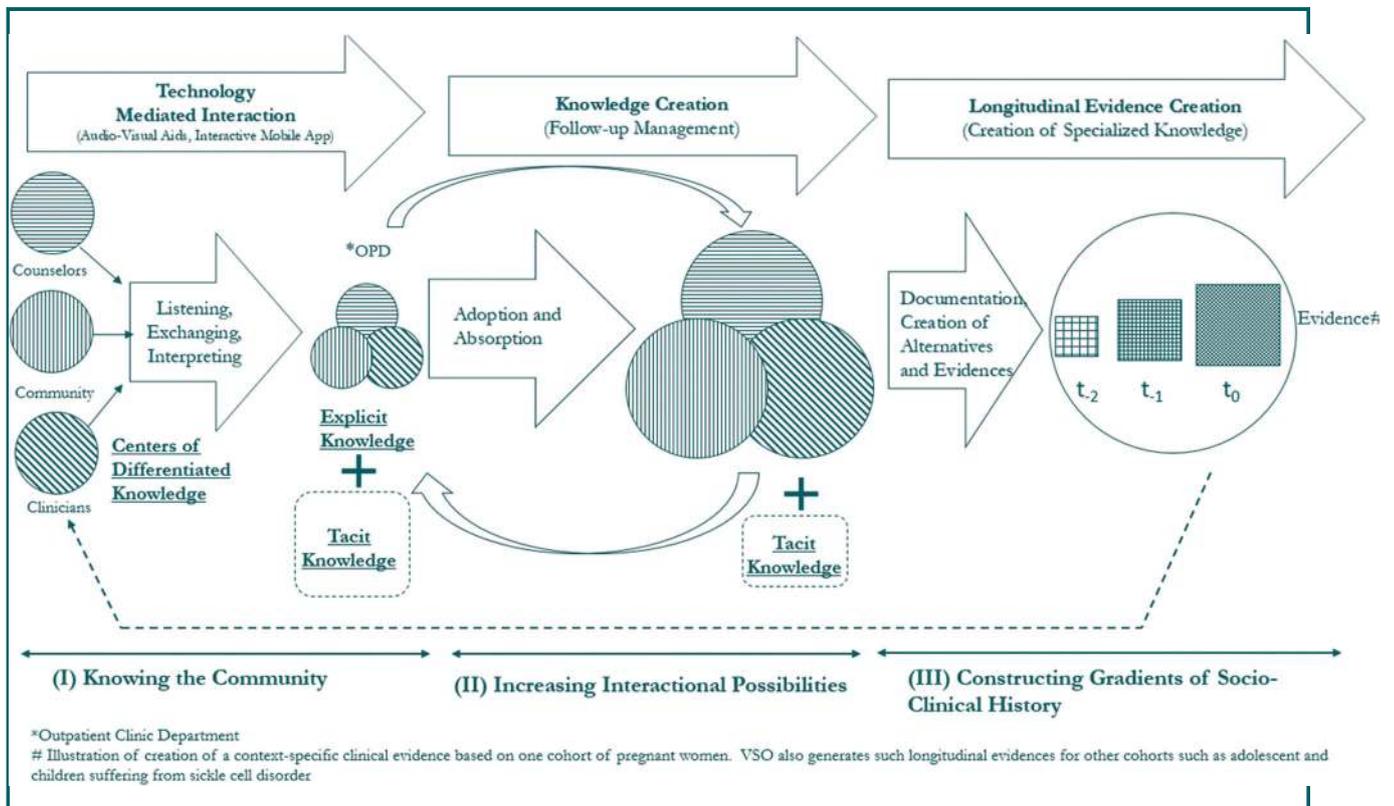
of field-level evidence and knowledge in the organization, which constitutes an important, technologically-enabled practice that distinguishes this knowledge practice. Identifying individuals in a pool, keeping track of their clinical history and exploring alternates together create gradients of information 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 our study, 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 health care institutions. Figure 1 depicts the resulting framework of the role of technological entwinement in knowledge practices by VSO.

Discussion

This study demonstrates that the ICT based interactions between actors at organizational boundaries and tribal patients could be a source of generative knowledge structures that create multiple specialized practices within an organization. As shown in the conceptual framework in Figure 1, these practices facilitate knowledge creation during interactions among expert physicians, front-line counselors and tribal patients, thus leading to progressive specializations and creation of EBM. This study acknowledges the significance of EBM and the documented generative knowledge structures for health care organizations

Figure 1 Role of ICT in knowledge creation practices at organizational boundaries



in emerging economies where tribal communities face a serious lack of access to state-of-the-art health care facilities. Furthermore, situating the study in a context that provides health care for a rare genetic disorder like sickle cell also presents an opportunity to exemplify how ICT intertwines with the knowledge creation practices at organizational boundaries in a challenging socio-cultural context. Following the seminal work by Nonaka (1994), several studies have invested in the research on knowledge creation and some have advanced the practices beyond organizational boundaries (Barley *et al.*, 2018; Carlile, 2002). This study contributes to the literature that details knowledge management practices in the health care sector (Nicolini *et al.*, 2008, Sheffield, 2008; Srivastava and Shainesh, 2015), by identifying interactions across organizational boundaries as a critical input to an integrative system that can support new and context-bound evidence in health care.

Figure 1 illustrates that, in the process of care in genetic and rare disorders, different actors adopt different truths, so it becomes necessary to find common ground during interactions. While patients focus on their social experiences of pain, allied practices, the physicians are more concerned with clinical complications. They depend on patients and their families to understand individual and epidemiologic forms of the disease. Such differences call for interpretive mediation. The front-line counselor, who hails from the tribal community, represents the third node, which recognizes the different versions of sickle cell disease and deploys interpretive and interactional skills to help bridge the divide between the physician and the patient. In the outdoor patient clinic's interactional space, patients come to comprehend the meaning of pain and sickle cell while interacting with the front-line counselors. The continuous informational exchange between the front-line counselors and the expert physician brings the physician closer to the community's social structure and cultural norms and enhances the front-line counselor's understanding of sickle cell disorder. Technological interventions such as videos and computing Tablets, lead to greater interactional proximity and partial integration of fragmented knowledge of the patient about a clinically complex disorder such as the sickle cell. The interventions also include registration, follow-up management and checking of the patient's medical progress and history. Hence, the first and second knowledge creation practices identified in the framework (Figure 1) – "knowing the community" and "increasing interactional possibilities," help to bridge the linguistic and dialogical divide. In such situations, ICT plays a critical role in the creation of knowledge at organizational boundaries by enabling the conversion of tacit "field-specific" perspectives to explicit concepts (Nonaka, 1994, p. 25).

We also find that the knowledge creation practices are not restricted to the socio-cultural and professional boundaries between the organization and tribal community. The third practice of "Constructing gradients of socio-clinical history" signals the significance of a longitudinal evidence creation (which is a by-product of the first two practices) in documenting and sharing the expert knowledge with other organizations. Such practices are essential, especially for health care organizations operating in emerging economies that lack proper resources and expertise to deal with such rare genetic disorders. In the upcoming sections, we explicate the significance of each of the practices with respect to the findings of our study.

Practice I: knowing the community

This practice establishes the initial common space and structure for interactions to prioritize *knowing the community*, beyond medico-clinical experiences. Our findings provide empirical evidence suggesting the significance of "Ba" in knowledge creation (Nonaka and Konno, 1998). The first practice i.e. "Knowing the community" signals how the shared knowledge space (or "Ba") gets activated through multiple ICT mediated interactions among the actors. Throughout the vignettes, we find that the ICT based practices such as showing videos, registering medical history in the mobile app, connecting on telephonic calls, create *shared spaces*, wherein the tacit issue of pain and social aspects of patients and their families are discussed. It enables VSO to make meaning of how the tribal community relates to pain. At one level, when the patient's history is recorded into the app, it also becomes a space to

record the patient's experience of the pain associated with the disease. On another level, the app also records the personal and social structure of the patient, which enables VSO to connect with the patient outside the organizational boundary and retain its connection with the patient and the community even after the patient is discharged. Furthermore, with continuous feedback emerging from the interactions among the front-line counselor, patient and the app, VSO ensures that the app improves its functioning versatility.

Similarly, we find that the practices of follow-up calls to the patients and showing video in groups generate a shared space ("Ba"), which enhances the understanding of the socio-cultural (and tacit) meanings that the community associates with this disease. Such practices enable the organizing of explicitly situated, tacit interactions that had been distributed and localized among actors previously (Figure 1). The fragmentation across actors, often with different socio-linguistic and professional origins, can represent a barrier, unless a common technological and tacit element combines these different contexts. The front-line counselor, along with the physician (Vignette 1), instead builds bridges by listening, exchanging, translating and interpreting – not just, as one physician's highlights, "clinically administering their lives." These practices initiate knowledge creation in the organization, represented through explicit overlaps among the expert, the front-line counselor and the tribal community during rich interactional practices. The technology creates an initial artifact, as represented by the digital entries of history that capture clinical and social realities to serve as a primer that can be extended in the future.

Practice II: increasing interactional possibilities

Over time and through multiple interactions, the organization enhances its knowledge pool. This leads to an increased awareness of clinical signals in patients, which help them prevent severe consequences and enhances familiarity of the front-line counselor with the clinical presentations exhibited by each patient and the physicians' experiences of potential clinical complexity and socio-environmental influences. It is apparent that the ICT based practices used by the VSO build on initial knowledge structures, and its situated practices are influenced by tacit knowledge. These practices offer the possibilities of new social and clinical facets, which are dynamically captured by evolving technological artifacts. Many patients request discharges or visit traditional healers; all such information is included in the technological artifact (the mobile-based app), which represents an acknowledgment of the clinical – cultural confluence in knowledge practices. Such instances, integrated into the information system, allow it to intermeditate a discursive social practice and indicate a granular possibility for creating new pieces of evidence.

Practice III: constructing gradients of Socio-Clinical history

Finally, technology also helps to 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 enable the organization to pursue greater clinical engagement with sickle cell mothers. In turn, a team of gynecologists, administrators, nurses and front-line counselors collectively seek to commit to new benchmarks of care. Similarly, other such health care organizations might create avenues for the specialization of care, should they expand the systems beyond a specific program management tool. Reflecting on the evolution in care practices since 2011, a senior doctor noted, regarding the use of hemoglobin levels as a benchmark, that "everyone knows the history and new standards. [...] [We] aggressively maintain a high level of hemoglobin among sickle cell mothers."

As [Figure 1](#) shows, these specializations, enabled by knowledge generation potential of ICT, provide clinical evidence and create opportunities to develop EBM practices for the field. As such, ICT in the VSO extends beyond the role of program management tools to include evidence creation efforts. As a result, the trajectory of knowledge 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.

Implications for practice

In the context of the marginal tribal community, this study identifies knowledge creation practices such as knowing the local community and utility of persistent dialogue using ICT. Such practices are critical for health care delivery for the resource-constrained context of emerging economies ([Yiu et al., 2018](#)). Organizational interfaces with the local community should be used as interactional opportunities, and by deploying ICT based practices, empathetic access to health care can be achieved in orphan diseases. In doing so, careful use of the local human resources such as front-line counselors and nurses can further enable organizations to bridge the human resource constraints and bring socio-cultural knowledge in clinical considerations. Finally, local health care institutions can be an important source of knowledge at the larger field, a level that may inform policymakers to devise an appropriate, need-based, culturally accommodative and participatory models of care delivery in the tribal areas. As the COVID-19 pandemic has shown, the convergence of technological and interactive opportunities at social boundaries has never been greater before.

Limitations and directions for future research

This work has some limitations that are typical in ethnographic studies. We know that ethnographic studies concern with “how things work” in organizations with a “relevance-to-practice” approach ([Watson, 2011](#), p. 202). Therefore, to the extent, the findings of this study are context-bound and may need a careful approach before application to different social settings. Hence, we suggest that studying local organizational practices in various socio-cultural settings may be critical for fulfilling the ambitious SDG #3. Further, future research may also explore the knowledge transfer processes within the professional boundaries and between expert physicians and front-line counselors from the community. Our focus on knowledge creation could also be extended to understand the transfer of knowledge in situated learnings of the community, which may enable some form of self-care in genetic disorders such as sickle cell disease.

Conclusion

Our study is situated in the literature on knowledge creation at organizational boundaries. We provide empirical evidence and theoretical insights on how inflow and outflow of knowledge ensure effective health care delivery ([Sheffield, 2008](#)), and how ICT based practices are used by frontline health care workers (here front-line counselors) and expert physicians in patient interaction and knowledge creation. We study how a health care organization interacts with marginalized tribal communities to deliver care for a rare genetic disorder called Sickle cell. Given the genetic origins of sickle cell disorder, the health care systems in developed economies track the cases at the neonatal stage. In contrast, such holistic tracking remains a challenge for emerging economies. Moreover, these economies are still on a path to develop effective health care ICT based practices and state-of-the-art infrastructure for delivering care to such communities.

Our study identifies some significant knowledge creation practices deployed by a health care organization to deliver care to the marginalized communities. Organizational efforts to engage with locally embedded tribal communities in clinical spaces often face challenges,

but as this study shows, there can be opportunities for knowledge creation. Through this study, we propose mechanisms to realize Nonaka's (1994) proposition suggesting the significance of organizational boundaries in knowledge creation. Our findings and the proposed framework demonstrate how tacitness emerges during the multiple interactions among the actors and how the ICT based practices capture it. Sickle cell disorder requires different care practices at different stages. By carefully attending these transitions through ICT based practices, VSO could generate sickle cell knowledge for similar organizations that may not have adequate resources, especially in the emerging economies context.

Using ICT based interventions, physicians and front-line counselors engage with the social and embodied experiences of the tribal community to initiate care processes, centered around the community. We observe that three technology-mediated knowledge practices provide a comprehensive mechanism of knowledge creation at organizational boundaries. First, "knowing the community" creates a knowledge structure for technology and human actors; it involves listening, exchanging, translating and interpreting sickle cells to prepare a common ground for actors to engage further. As tacit dimensions are critical to practice-based knowledge in organizing care, therefore technological entwinements with human actors can become a source of generative knowledge in subsequent interactions at organizational boundaries. Second, interactions in the clinic through the practice of "increasing interactional engagement" enable service delivery and creating context-specific knowledge in a longitudinal manner. Third, the organization develops specialization and creates EBM knowledge sets by "constructing individual and collective socio-clinical histories" intermediated by arrays of ICT entwinements. These practices not only create context-specific knowledge regarding a genetic disorder, but they also generate usable knowledge for other similar organizations.

Notes

1. First author conducted the ethnography for over a year, during 2016-2018.
2. 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.
3. 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.
4. Ischemic injury: is restriction of blood supply, and hence oxygen, to tissues leading to dysfunction of tissues
5. Video: A 20 min play showing the pain of sickle cell and the response of a tribal family. VSO routine use audio-visual aids in elaborating clinical and social dimension of important health challenges to the community.
6. HPLC: Acronym for high-performance liquid chromatography method of sickle cell test. This is used to identify the type of hemoglobin in blood.

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Further reading

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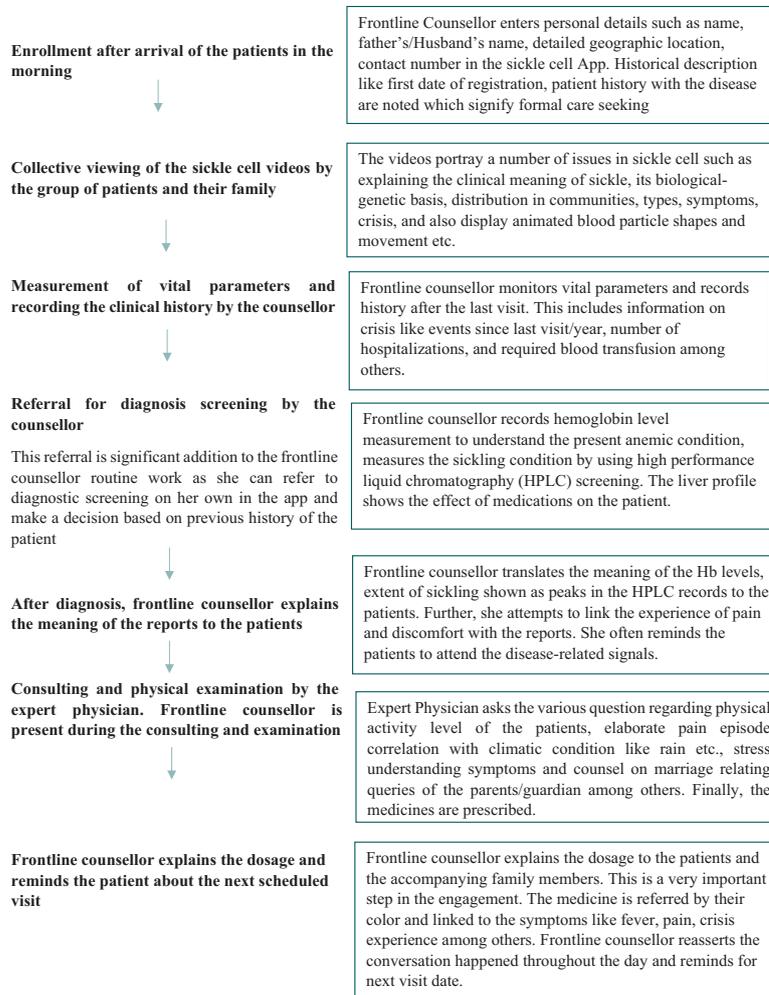
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Appendix 1. Flow of the outpatient



Appendix 2. Additional vignettes

Vignette II

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

A 21-year-old married female patient arrives at the outdoor patient clinic of VSO. Upon being repeatedly requested to show her file, she informs the frontline counselor that she is “without any file.” VSO recognizes that paper files have their own importance as it can become very useful and handy for patients living *in rural tribal areas* “especially if patients need emergency care at any other center or in case of referrals to higher center,” as stressed by the expert physician. However, without any delay, the frontline counselor opens the digital records of the patient and engages with the patient. She empathetically asks about the patient’s present condition. The purpose is to identify any discomforting experiences such as pain or fever or any other symptom that must be attended immediately. Observing little or no response from the patient informs the frontline counselor that “the patient needs to be counseled more.” This quick evaluation by the frontline counselor is an important *tacit* practice. She understands that the patient needs to interact and trains the patient further so that they can express their problems better. The expert physician also acknowledges that the patients should interact more because the significance of the previous history in hereditary disorders is critical and VSO cannot administer medical intervention based on such limited interactions.

Keeping the *digital* history of patients is an important organizational practice. The retrieval of information from the digital records revealed a recent “inability to make follow-up visits” by the patient. It was noted that the patient had missed two scheduled visits in the past two months. Due to a change in her location from the address mentioned in the registration details, VSO could not reach out to her during the follow-up calls. A few days back, the frontline counselor retrieved the contact details of the patient’s maternal home and could finally reach out to her through a phone call. The patient told me that she was living with her mother because of some personal reasons. On the day of the visit, the patient had traveled 55 km to reach VSO. This indicates the value of follow-up communication and maintaining address and contact details of the patient’s in-laws, as well as maternal homes. It also indicates the necessity to weave in the social and family structure of the patient into the ICT enabled practices. Clinically, it was found that the patient required emergency medication of hydroxyurea and her vaccination schedules were also imminent. The use of digital records is extremely critical in keeping the track of both – clinical and personal journey of the patient to ensure effective health care delivery and evidence creation in providing sickle cell care to pregnant women (Refer Practices I and II in [Figure 1](#)).

Vignette III

Organizational meetings and research paper seminars: revealing insights on alternate diagnosis application to screen sickle cell in newborn

As a commitment to understanding the severity of sickle cell distribution in the tribal population, VSO regularly engages with all the relevant stakeholders in the field of medicine. In one of the meetings, the expert physician emphasizes screening the newborn child for sickle cell disease. As the neonatal mortality rate is very high, it highlights the critical importance of an early diagnosis. The expert physician elaborates on the “unknown” in the pattern of sickle cell in neonatal care. VSO partnered with other organizations to develop a novel device that provides more accurate and speedy diagnostic of sickle cell disorder in newborn. Based on a rapid test, of a cohort of over 200 children at VSO, an initial estimation revealed that “early diagnosis can reduce the mortality rate by 70%.” Other centers that partnered in this study shared their insights as well. This technological pooling of evidence facilitated the value of newborn screening for sickle cell disorder. At present another longitudinal study is ongoing, and VSO believes that through careful observations, data collection, communication, follow-up and clinical management, it could provide better insights to manage sickle cell disorder. This highlights the role of introducing new ICT enabled practices in the clinical spaces which focus on data management and analysis. Further, it can aid the preparation of a clinical history of early diagnosed neonates (Refer to Practice III reported in [Figure 1](#)) as they advance in their life.

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