

## **TRANSLATION OF A COMMUNITY PALLIATIVE CARE INTERVENTION: EXPERIENCE FROM WEST BENGAL, INDIA**

**Abstract.** The community form of palliative care first constructed in Kerala, India has gained recognition, worldwide. Although it is the subject of important claims about its replicability elsewhere, little effort has gone into studying how this might occur. We conducted an in-depth case study of Sanjeevani, a community-based palliative care organization in Nadia district, West Bengal (India), that is modelled on the Kerala approach. Drawing on translation studies, we attend to under-examined aspects of the transfer of a community palliative care intervention into a new geographic and institutional context. We examine the translator's symbolic power and how it counteracts the organizational challenges around socio-economic conditions and weak institutional histories of civil society organizing. We show how the translation is an ongoing, dynamic process, infused with values of occupational prestige and camaraderie and shaped by emergent vertical solidarities among members. We find that the translated form is a hybrid of horizontal and vertical solidarities. Our findings have significant implications for how we understand the relationship between locations, institutional histories, and healthcare interventions. We contribute to translation studies in healthcare, and particularly to conversations about the transfer or 'roll out' of palliative care interventions from one geography to another.

**Keywords:** Community-based organizations, palliative care, translation, India

## 1. Introduction

This study examines the translation of a community-based palliative care intervention into a new institutional context. Community-based healthcare approaches have been widely recognized since the Alma Alta Declaration in 1978, which emphasized the bottom-up role of communities in improving their health status and reaching a state of physical, mental, and social well-being (Abel et al., 2013; Bardach et al., 2017; Draper et al., 2010; Rifkin, 1986; World Health Organization, 1978). Yet, even when effective ideas are identified, they seldom travel between contexts, and have variable and often disappointing results when replicated (Lawrence, 2017). Indeed, public health researchers increasingly highlight the problems of uncritical policy and practice transfer, emphasizing instead the *translation* of interventions (e.g. Dolcini et al., 2010; Kothari and Armstrong, 2011; Mannell, 2014; Montesanti et al., 2015). Unlike studies of replication, diffusion, or transfer that denote actors as passive recipients of ideas, translation approaches emphasize context and actors' reflexivity (Czarniawska and Joerges, 1996; Sahlin and Wedlin, 2008).

Organizational forms have a direct bearing on an intervention's adoption and effectiveness in the target setting (Tracey et al., 2018). We define organizational forms as "archetypal configurations of structures and practices that are given coherence by underlying values, and that are regarded as appropriate within an institutional context" (Greenwood and Suddaby 2006, p.30). Accordingly, a community form is a distinct organizational configuration typified by consensus-building practices, and non-hierarchical member relations and values (Armstrong and Kothari, 2011; Marquis et al., 2011). Research informs us of the strategic challenges in translating community forms, such as establishing community partnerships, gathering local information, and transforming frameworks for local adoption (e.g. Draper et al, 2010; Kothari and Armstrong, 2011; Montesanti et al., 2015). However, we rarely attend to the construction of the new organizational form during

translation, and the social, political and historical conditions that shape this translation process.

We examine the translation of a community-based palliative care intervention into Nadia district, West Bengal, India. Palliative care is an approach to improving the quality of life of patients and families with life-limiting conditions (World Health Organization, 2017). Community-based care which emerged in Kerala, India has received widespread attention as a contextually appropriate, resource-effective alternative to hospital and hospice-based approaches to palliative care (Quality of Death Index, 2010, 2015; Kumar, 2013). Three key practices characterize the community approach. First, community members – such as farmers, bus drivers, teachers - are the locus of care-giving, decision-making and fund-raising, with medical professionals providing need-based support. Second, palliative care is conceptualized as ‘total care’, including medical, social, and financial support, rehabilitation and bereavement services for patients and families. In this manner, over two decades, Kerala has expanded palliative services to a wide-range of diagnostic groups including cancer, chronic cardiovascular and renal conditions, mental health issues, geriatric needs, and paraplegia. Third, this model involves integrating community organizations into public health systems wherein they collaborate with local self-governing institutions for care delivery. A measure of the success of the model was seen in 2008, when in response to bottom-up advocacy by community organizations, the Kerala state government passed a landmark policy mandating that state-funded primary health centres be equipped with professionals trained in palliative care and resourced with locally required opioids (Kumar, 2013; Vijay and Kulkarni, 2012).

In these ways, the Kerala palliative care movement has mobilized over 15000 volunteers, 65 physicians, and 180 nurses in over 200 community organizations, to cover more than 60% of the patient population across all 14 districts of Kerala, making it the only Indian state to have palliative care in every district (Quality of Death Report, 2015). In sharp

contrast, coverage in the rest of India (where palliative care is predominantly provided through hospices or hospitals) is less than 2-3%, with most states having no known palliative care provision (McDermott et al., 2008; Rajagopal, 2015). The large scale and scope of Kerala's palliative care model has strengthened global discourse on community-based palliative care interventions as a public health strategy (e.g. Abel et al., 2013; Sallnow et al., 2012), with attempts to replicate it not only in India, but also in Bangladesh, Switzerland, Sri Lanka, and Thailand. Simultaneously, questions have been raised about the transferability of the Kerala model to other institutional contexts (Sallnow et al., 2010).

Three key findings emerge from our study. First, our institutional analysis delineates the organizational challenges posed by socio-economic conditions and weak institutional histories of civil society organizing. The translator's employment of symbolic power legitimates the nascent community form in this institutional context. Second, unlike the community form in Kerala typified by horizontal linkages, the community form in Nadia emerges as a *hybrid* of vertical and horizontal solidarities. Third, translation here is as an ongoing, dynamic process, infused with values of occupational prestige and camaraderie and shaped by emergent vertical solidarities. Such an understanding of translation processes adds texture to discussions on the transfer and 'roll out' of best practices and frameworks beyond the institutional contexts in which they originate (Abel et al., 2013; Montesanti et al., 2015).

## **2. Theoretical Framework**

We define translation as the selective interpretations of new ideas, practices, or forms that are contextually appropriate or may involve "local adaptations and transformations" (Zilber, 2006, p.300). Accordingly, ideas do not diffuse in a vacuum, and actors are not simply passive recipients of new practices. Rather, translation studies attend to how ideas and practices travel and are transformed from one institutional context to another through actors' interactive, negotiated processes (Czarniawska and Joerges, 1996; Hwang and Suarez, 2005).

Translation is therefore a doubly contextualized process, reflecting both the historical and cultural conditions within which an idea emerges, and the conditions to which it is transposed (Wolf and Fukari, 2007). To translate, then, is to construct anew, as variations take on different forms and meanings in different institutional contexts (Czarniawska and Joerges, 1996; Sahlin and Wedlin, 2008). Power and domination underpin the act of translation, as the translator's social position and prestige influence her visibility (or invisibility) and acceptability (Wolf and Fukari, 2007). Symbolic capital is a specific form of capital commonly designated as prestige and authority. Symbolic power then arises out of symbolic capital as the belief "by virtue of which persons wielding authority are endowed with prestige" (Bourdieu and Wacquant, 2013, p. 299).

The translation of a new form into a distinct institutional context presents unique challenges compared to introducing it to a similar institutional context, or translating subsidiaries, chapters, or franchises of an existing organization (Tracey et al., 2018). Additionally, translation into a new institutional context presents specific challenges in the case of community organizations. First, it is problematic to assume the *a priori* presence in the target field setting of a cohesive community with shared purpose. While actors may recognize mutual interests and a potential for shared organization, this does not necessarily translate into coordinated and effective action (Hardy, 1994). Thus, not only must an idea travel across boundaries, but transferring a community form also involves multiple actors coming together to co-ordinate and engage in productive work. Second, community forms are marked by specific organizing processes that are shaped by geographies and the histories of organizing (Greve and Rao, 2014; Marquis et al., 2011). Accordingly, communities vary in their institutional infrastructure – such as legal infrastructure, presence of other voluntary organizations, and intra-community relations – for collective action (Greve and Rao, 2012, 2014). Finally, even after a community form is seeded, organizing may be reduced to a few

individuals' volunteerism, and collective momentum may not be maintained (Aveling et al., 2012). How then are community-based healthcare organizations translated across distinct institutional contexts?

### **3. Empirical context**

Our study is set in West Bengal, a state in eastern India. Nadia, the focus geography of our study, has a population of 5,167,600 (~5.66% of West Bengal's population) and is one of 21 administrative districts of West Bengal. As with the rest of India, healthcare in West Bengal is largely privatized and accessed through out-of-pocket expenses (Garg and Karan, 2008). The Sanjeevani Palliative Care Society (henceforth, Sanjeevani), inaugurated on 22<sup>nd</sup> September 2014, was the first experiment in community mobilization for palliative care in West Bengal, and among the few nascent experiments outside Kerala. Sanjeevani (meaning "life-giving") was spearheaded by the District Magistrate of Nadia, in collaboration with physicians from the local chapter of the Indian Medical Association, and the Institute of Palliative Medicine (IPM), Kerala. Sanjeevani was registered as a non-government organization. Three patient categories in Nadia were identified for inclusion, those with advanced cancer, chronic renal conditions, and the chronically bed-ridden. Non-communicable diseases account for more than 52% of illnesses within Nadia (Pratichi Institute, 2012). Patients presented at advanced stages of chronic and life-threatening conditions, rendering the need for palliative care services more immediate and essential (McDermott et al., 2008).

### **4. Research Methods**

We combine primary and secondary analysis in this study. The research team has been involved in different ways in studying Kerala's community form emergence and its translation to Nadia. We thus use our publications, other published sources, and reflections from our engagement in these two sites to inform our secondary analysis (Aveling et al.,

2017; Campbell and Cornish, 2012). We also draw upon primary data from field observations, interviews, and personal communications between various actors in Nadia. Our study spanned 29 months (June 2014-November 2016), commencing with participation in volunteer trainings prior to the official founding of Sanjeevani, and continued until we reached empirical and theoretical saturation (Erlandson et al., 1993). Ethics approval was obtained from the university with which two authors are affiliated. 22 participants were sampled purposively for semi-structured interviews to understand different stakeholders' perspectives. Accordingly, interviews were conducted with the District Magistrate, physicians of the local Indian Medical Association, volunteers and nurses, and visiting members of IPM. Interviews (lasting 20-90 minutes) were in English (4) and Bengali (18) and were audio-recorded. We conducted eight field visits, involving attendance at awareness workshops, training sessions, review meetings, and Sanjeevani's foundation day. In total, Krishnagar municipality and six of 30 panchayats (panchayat is a village council with elected representatives) were visited. Home care teams were accompanied during 40 patients' home visits. These field visits enabled observation of participants' interactions, collective dynamics, and the emergence of tensions, at various stages. Multiple interactions with patients and families occurred during home care visits.

Analysis proceeded through various stages alongside data collection. First, analysing institutional legacies that shape communities (Greve and Rao, 2014), we distinguished between the institutional contexts in Kerala and West Bengal. Second, developing a thick description of the Sanjeevani case, we identified aspects of the community form (in terms of practices and relational structures) that materialized in Nadia. Finally, we used constant comparative analysis to identify major themes (Strauss and Corbin, 1990). At this stage, we identified resource mobilization, low-levels of legitimacy, top-down organizing, teams and team leaders, occupational prestige and camaraderie, as salient themes. Iterating between

theory and data, we clustered these themes into interpretive categories relevant to the translation process. As per Erlandson et al. (1993), we established trustworthiness of our findings through the triangulation of data sources (e.g. diverse stakeholders), multiple methods (interviews across different time periods, observations), and researcher triangulation. We maintain participants' real names, and use pseudonyms (indicated with an asterisk) in certain cases where confidentiality was requested.

## **5. Institutional Context for Community-Based Organizing in Kerala and West Bengal**

We focused our analysis of the institutional contexts of Kerala and West Bengal by examining the institutional legacies of voluntary organizations, intra-community relations, and legal structures pertaining to healthcare (Greve and Rao, 2014). We also compared health infrastructure in both contexts. Table 1 provides a summary.

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Kerala presents a unique socio-political and historical context for a community form. The state is characterized by high levels of literacy and health indicators (see Table 1) comparable with many developed countries (India Human Development Report, 2011). Moreover, Kerala has the highest per capita expenditure on health care in India (Jeffrey, 2011). These social indicators have been attributed to a vibrant civil society (characterised by a high density of co-operatives and community organizations) and a history of mobilizing for rights, especially in healthcare (Santhosh, 2016; Vijay, 2012). Such social structures decrease the costs of collective action and enhance shared logics of action and opportunities for resource mobilization (Greve and Rao, 2014). Further, for decades, the Kerala government has invested in health infrastructure with robust, functioning public health facilities and there have been numerous experiments with community organizations in healthcare (Jeffrey, 2011). Thus, a community approach, albeit novel to the palliative care field, was a legitimate organizational template in Kerala.

In contrast, West Bengal has weaker histories of community-based organizing and institutional infrastructure for healthcare. Studies point to Bengal's 'party-society' logic, characterized by patron-client relationships between the Bengali population (especially in rural areas) and the two regionally dominant political parties (Bhattacharya, 2009; Roy, 2012). An outcome of this clientalism is that political parties tend to displace other competing channels of public transactions such as civil society organizations (Bhattacharya, 2009).

Nadia district, where the Sanjeevani experiment unfolds, is predominantly a rural region. Patients we tracked in Nadia district typically travelled to Kolkata (the capital city of West Bengal, approximately 150 kilometers from Krishnagar - the Nadia district headquarters) for treatment. Having done field work in different parts of Kerala and in Nadia, we observed the stark destitution and lack of access to basic healthcare facilities at Nadia. Patients' families were typically engaged in agriculture, masonry, and similar forms of manual wage labour. Several availed of the government funded Mahatma Gandhi National Rural Employment Guarantee Act Scheme that guarantees 100 days of work per year. Patients with curable conditions were deemed incurable by family members, due to poor health literacy, misinformation from middle-men, and economic difficulties of accessing robust healthcare. Thus, we see Sanjeevani germinate in a vastly different socio-political context from the source context in Kerala.

## **6. Key Moments of Translation**

We identified three moments that influenced the translation of community-based palliative care practices to Nadia: the translator's enactment of symbolic power, translating member relations, and translating social participation.

### **6.1. Translator's Enactment of Symbolic Power**

*Enabling Resource Mobilization.* The District Magistrate (DM), P.B. Salim played a pivotal role in crafting Sanjeevani as a community form in Nadia. Upon taking office at

Nadia in March 2014, Salim invited Suresh Kumar, a pioneering palliative care physician and the founding Director of the Institute of Palliative Medicine, Kerala, to hold an initial core meeting with local stakeholders (including physicians, activists and volunteer social workers) Salim had identified. With his knowledge of over 25 years of community-based organizing, Suresh observed:

This involvement [of the DM] resulted in a faster mobilization of resources, as compared to what CBOs [community-based organizations] grapple with in Kerala, as community volunteers spend a considerable amount of time in the first year seeking funding and core volunteers, besides seeking legitimacy for their efforts

A DM's position is that of a "mini-monarch" within the Indian Administrative Services hierarchy, with jurisdiction over almost 50 departments including agriculture, law and order, revenue, welfare and development (Bandopadhyay, 2006, p. 4851). Since DMs typically spend a considerable amount of time dealing with immediate, every-day issues of law and order and public grievances, they are less likely to be involved in long-term development and welfare projects. However, Salim's welfare projects for marginalized populations during previous official deputations had earned him the epithet of "People's Collector" (Collector is another title for District Magistrate). At Nadia, prior to the launch of Sanjeevani, he initiated the Sabar Shouchagar Project ('Toilet for Everyone'), transforming Nadia into India's first open defecation-free district (Vijay and Ghosh, 2017) and subsequently winning the United Nations Public Services Award 2016.

Thus, Salim's involvement with Sanjeevani garnered considerable attention, in addition to media coverage. The initial awareness program saw the enrollment of over 1000 participants from diverse backgrounds, such as students, home-makers, teachers, and local social workers, who attended the kick-off meeting in May 2014. Thereafter awareness camps and training programmes were held in public auditoriums, such as the Zilla Parishad Bhavan. Sanjeevani's launch in September 2014 was a grand function at the district auditorium, attended by more

than a dozen elected political representatives. At the time of inauguration, Sanjeevani had the initial support of 14 physicians and two nurses (professional resources that are acutely short in India), along with over 150 master trainers and 1000 trained community volunteers. Master trainers trained other interested volunteers in their own neighborhoods. Two ambulances were donated by local elected political representatives.

*Overcoming Low Legitimacy.* Most of our participants had not heard of the Kerala model prior to its introduction in Nadia. Additionally, during training programs and awareness workshops, participants raised doubts about whether such an initiative would materialize in West Bengal. For instance, at a training, a participant openly stated, “*in Bengal we have a political society, not a civil society. I am not sure this will work*”. Such articulations were tethered to views that the institutional context was not conducive to a civil society organization without any political party affiliation.

During pilot home visits to survey potential patients’ needs, volunteers were interrogated by family members on which political party they represented. In the absence of a political affiliation, families expressed skepticism about the volunteers’ intentions. A physician shared concerns about this lack of legitimacy for non-governmental organizations (NGOs):

A lot of NGOs have laundered money with malpractices. People do not hold high regard for NGOs, because, in general, they are inclined towards corruption and malpractices. We wanted to steer clear of an NGO name, but then for registration we need that.

In one case, a patient’s family expected economic support and did not comprehend the need for home-based palliative care, insisting that Sanjeevani provide financial aid for the patient’s treatment. When no financial aid was in sight after a few visits, the family warned the team that “*don't ever come back to our house*” (*Tomra ar ashbe na amader barite*). Such harsh encounters in the early stages created anxieties among volunteers regarding their work and Sanjeevani’s viability.

Under such circumstances, the DM's affiliation played a vital role in signaling and legitimating Sanjeevani's efforts. Sanghamitra was a palliative care physician working independently in Kolkata. She had experienced first-hand the difficulties of finding volunteer and nursing support. Sanghamitra provided initial support for one year to Sanjeevani and recognized the symbolic power of the DM's involvement in attracting volunteers and patients. She observed: "*The District Magistrate was involved. People thought it has to be big, and it has to be something to do with good work*".

Thus, Salim's symbolic capital was manifest as Sanjeevani took root. Towards the end of Salim's tenure in Nadia and impending relocation to another district, our participants were anxious about Sanjeevani's sustainability in Salim's absence and shared anxieties over his successor. After his tenure, Salim continued to visit Sanjeevani on occasion, during which he helped team members address pressing challenges, such as finances. Sanjeevani members explicitly articulated that Salim's presence and periodic visits were pivotal to their motivation and the initiative's sustainability. We thus contend that in this distinct institutional context, the translator's symbolic power was significant in mobilizing the necessary conditions of social interaction to realize the intervention (Wolf and Fukari, 2007).

## **6.2. Hybridizing Member Relations: Emergent Vertical and Horizontal Solidarities**

*Top-down Organizing.* At Nadia, the DM mobilized a coalition comprising local social activists and physicians from the Indian Medical Association's local chapter. This coalition became Sanjeevani's core committee, driving further activities. IPM, a World Health Organization Collaborating Center, provided specific inputs on the technical and organizational aspects from the earliest training phases at Nadia. After the official launch, IPM members visited Sanjeevani bi-monthly for the first six months, and then quarterly, accompanying home-care teams, and participating in core committee meetings, trainings, and awareness programs.

Revealing their social distance, community volunteers referred to the DM and physicians with honorifics such as “Honourable”, “Sir”, with one volunteer sharing that, “*It feels as though they [physicians] are helping us like Gods would. We have their blessings. They support us*”. Even allowing for a false and front-stage reverence here, such statements illustrate an inherent sense of social power (cf. Scott, 1985). In Kerala, these leadership accounts were less salient within the community form. Indeed, Kerala’s earliest community organizations in Manjeri, Nilambur and Kozhikode explicitly espoused guidelines that “All are equal”, “There is no leader”, “Every volunteer is a leader” (Rajagopal and Kumar, 1999), inscribing these guidelines into organizations’ by-laws, and training manuals (Vijay, 2012).

*Teams and Team Leader.* Marking a discursive variation in the transfer of palliative care from Kerala to Nadia, the term “community” itself was almost absent in our participants’ narratives. Rather the term “team” was used repeatedly. The discourse of community is more entrenched in Kerala, which has a history of community mobilization programmes, especially in healthcare (Jeffrey, 2011). In contrast, the more ubiquitous and familiar concept of “team” prevailed in Nadia. Consistent with the team metaphor, the team leader’s role at Sanjeevani was to motivate, mobilize and co-ordinate. Consider how Mrinal, a unit coordinator, describes organizing at the unit level:

When I hear that there is a patient, within 2-5 minutes, our volunteers will go to that patient ... Our volunteers collect the necessary information and bring it to us. We have a team leader, they’ll send them to the team leader. In 5 minutes, the message will reach us. We cover 143 villages, in every village, we have 30-40 patient volunteers.

Mrinal’s description illustrates the hierarchies in information flow and decision-making we observed. Although co-ordination is essential to any such geographically dispersed activities, community organizations typically decentralize decision-making, emphasizing horizontal linkages and deliberative participation (Aveling et al., 2017). For instance, in Kerala’s palliative care community organizations, coordinator or administrative

positions may be rotated among members (Vijay, 2012). At Sanjeevani, the village-level volunteers are crucial nodes for patients, but unit coordinators like Mrinal emerged as leader figures.

Thus, the top-down seeding of Sanjeevani by a powerful, influential coalition comprising the DM, physicians and the IPM, created distinct vertical linkages with associated vocabularies of team and team leader.

### **6.3. Translating Social Participation: Occupational Prestige and Camaraderie**

How did social participation cohere amidst considerable material difficulties and top-down seeding of community organizing? Our findings suggest that newfound occupational prestige and camaraderie mobilized and constituted social participation. Sanjeevani's volunteers came from diverse backgrounds including retired school teachers, home-makers, young unemployed graduates, and activists, with a greater number of female volunteers. Several volunteers were from economically-deprived backgrounds. Sharmishta\*, a volunteer shared her situation:

We come from a BPL [Below Poverty Line] family. My husband does odd jobs at people's houses. We have personal problems at home, but I love this work so I continue to do it. My husband never prevents me from working. In fact, I used to leave my baby at home. I perform all household duties, take care of my baby and then come here. Most of us do this. But I want to do this, because I love the job.

Sharmishta was unemployed and had attended the Sanjeevani training sessions with her infant. Since the 1990s, West Bengal has faced fractured industrial growth and increased unemployment. Consequently, like Sharmishta and her husband, many are compelled to seek employment in the informal sector, with commensurately lower wages (Sen, 2009).

*Occupational Prestige.* Our participants shared with us the respect and status they garnered through their care labour. For some female volunteers, engaging in Sanjeevani's work meant breaching the domestic sphere, and garnering respect from their families for the care they gave. Consider Moumita\*: “*We feel good because despite being housewives, we*

*can go out and stand beside people who need support.*” Moumita reveals how women, otherwise confined to the domestic sphere, can now engage in the public sphere.

A distinctive feature at Sanjeevani was the practice of designing and wearing uniforms adopted by the volunteers and nurses. During our visit in October 2015, we were intrigued by the cream front-and-back aprons and sashes that volunteers were wearing with *Sanjeevani Palliative Care Society* imprinted. By November 2016, the nurses had a distinct dark blue salwar kameez with a white coat that distinguished them from the volunteers.

Papia\*, a nurse, describes this sartorial change:

Earlier when we used to wear the apron while visiting patients, people did not give us much importance. But now, when we go in a group in this uniform, people approach us. This gives us motivation to work.

Uniforms are important status markers in the workplace, delineating occupational boundaries and playing a role in the construction of professional identities (Rafaelli and Pratt, 1993; Timmons and East, 2011). Papia had undertaken a six-month vocational training in nursing along with her Bachelors and Masters degrees. With her new volunteer work as a nurse with Sanjeevani, Papia finds the uniform a means to create an occupational hierarchy. The cream apron that both volunteers and nurses wore is no longer good enough; the uniforms give them importance. Ghazal\*, a volunteer nurse, who was “unemployed and sitting at home” before joining Sanjeevani, justifies the uniform as follows:

When we are going to nurse someone, we should look like a nurse. If I wear a bright red *churidar* [traditional attire] and visit a patient, it does not look nice. Our uniform gives us an identity. Many people do not know about Sanjeevani, but when they see us in this blue uniform, they ask us about palliative care, they understand about Sanjeevani. This helps us to spread our work among the people.

The uniform here is an emblematic visible symbol by which a lay person can identify an occupational boundary, increasing the prestige of the nurse’s work (Timmons and East, 2011). Ghazal is not paid for her work, but she states that she derives meaning from her engagement with patients. The uniform produces a ‘stratified homogeneity’, distinguishing

the nurses from other volunteers and indicating status and hierarchy, and producing a collective identity within the group (Rafaelli and Pratt, 1993). Worth consideration is that the uniform is coloured blue and white - the colour code of West Bengal's ruling party, the Trinamool Congress. Mamata Banerjee, Chief Minister of West Bengal, and head of the Trinamool Congress, is quintessentially clad in white sarees with blue borders, and has been known to endorse a uniform colour code, painting government buildings, footpaths, flyovers, taxis, bus stops and tree trunks in blue and white (Rana, 2012). In a 'party society' that survives on political patronage, the hidden transcripts of the nurses' blue and white uniforms seem to have a deeper significance.

*Camaraderie.* Volunteers also reported a shared sense of camaraderie with other volunteers and the excitement of getting out of their homes for a good cause. Mirroring a common narrative of how volunteers found it meaningful to spend time with patients, Sujata a nurse and unit coordinator, explained:

There are patients whose families do not care for them. When we go and talk to them, they feel very happy ... For them, one week's wait was a long time. They share their thoughts and feelings with us, not with their family members. They tell us about their pains and griefs and we try to console them. They say that they don't need medicines. They just want us to come and chat with them. This is very motivating.

This form of social support provided multiple benefits to patients, including access to ambulance transport, free medication for a destitute family, pain relief by the visiting nurses home care team, and moral and spiritual support from the volunteers. Volunteers spent time with abandoned, elderly patients and read out from scriptures of the patient's religion. Volunteers enabled patients' access to chemotherapy and dialysis provided at a subsidized cost at the district hospital, a service of which many patients were unaware. To make use of this facility, a patient's family had to get a document from the panchayat affirming their need for a subsidy. If the family was illiterate, or hard-pressed because the breadwinner was sick, Sanjeevani volunteers helped families with panchayat procedures.

These practices which produced sociality were not just enacted between volunteers and patients, but also among volunteers. Rinku with 9 years of prior nursing experience shared:

I wanted to work there; I did not want money. I just liked the job. I am that kind of a person, who wants to love everyone. Elderly people – I like to talk to them. Listening to them talk about their griefs would wet my eyes. I could empathise with them. When I visit the patients, I talk a lot with them. I make them laugh when they are sad. All these people are there with me. They also laugh at my jokes and that comforts the patients.

Rinku describes a collective production of comfort and conviviality at the site of caregiving.

She elaborates,

I love this work so much that when I am at home, I feel very bored. Whenever I am on duty, and I visit patients, all my boredom vanishes and I am really happy. More than 12 hours a day I stay busy with this work. I rarely stay at home. Even after my duty is over, we stay back, chat with each other for an hour and then go home.

Ghazal agrees: *“We share a strong bond of friendship. Most of us are students. So, there is an energy in us ... Gossiping came very naturally to me. Sometimes even the patients' parents sit with us and participate in our stories and gossips. That is how our work is spreading.”* Sanjeevani volunteers expanded these affective spaces beyond palliative care provision through various ceremonies and symbolic rituals, such as an annual picnic.

Volunteers explained how they helped each other out if there were personal difficulties at home such as an illness or tragedy (like a house fire). On World Hospice and Palliative Care Day, volunteers identified new palliative patients and took sweets to patients' homes.

Intriguingly, on Raksha Bandhan, a festival in India where sisters tie a *rakhee* (a wrist band) on their brothers with the vow that the brothers will look after them, Sanjeevani volunteers took *rakhees* for patients to tie on the volunteers' wrists. Volunteers partnered with local social work organizations (e.g., the Lions Club) to distribute wheelchairs to those in need, and organized blood donation camps. For Christmas, volunteers organized camps at a fair where, in addition to spreading awareness about palliative care, they served as a nodal point for diverse activities like first aid and keeping track of lost children.

#### 6.4. Impact

Sanjeevani commenced in September 2014 in Krishnanagar municipality and seven adjoining panchayats. By November 2016, Sanjeevani functioned with approximately 900 volunteers through eight units encompassing 30 panchayats. Each unit had a coordinator selected by the core committee. Consistent with Kerala's community form, Sanjeevani's participation evolved with volunteers becoming the locus of care-giving and decision-making. Local volunteers surveyed neighbourhoods for patients, identified needs, mapped home-care schedules, maintained regular contact with families, and provided updates to home care teams. Sanjeevani held participatory monthly review meetings and general meetings where volunteers deliberated on organizational problems, such as challenges in identifying patients, recruitment of new volunteers, or difficulties with getting a nurse for their unit.

Two points of departure from the Kerala model surfaced. First, from the earliest days in Kerala, actors articulated that "all members are equal", "there is no leader", or "all volunteers are leaders" (Rajagopal and Kumar, 1999; Vijay, 2012). Indeed, the first community organization in Kerala at Nilambur, continues to run with predominantly non-medical professionals like farmers, teachers, bus-drivers and so on. Nadia, by contrast, was seeded by a distinct leader figure. Moreover, physicians were not just necessary professional support, but also pivotal to Sanjeevani's day-to-day operations. Second, the Kerala model thrives on micro-funding often of as little as Rupees 10 (21 US cents), raised from local subaltern actors (Quality of Death Report, 2010). Volunteers in Kerala emphasize the need for community-based micro-funding, to create community ownership (Vijay, 2012). Given the degree of destitution, Sanjeevani members reported difficulties in local fund-raising and primary funding came from physicians, local politicians and philanthropists. Table 2 outlines key distinctions between the Kerala community form and Sanjeevani.

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## 7. Discussion

In this research, we analyzed how the dynamics of translation influenced the transfer of a community form for palliative care to Nadia, in West Bengal. We now explore three key contributions from our study. First, our research extends contemporary discussions which suggest a shift from an analytic focus on *transfer* of healthcare interventions from a dominant context to peripheral contexts, and towards *translation* processes (e.g. Kothari and Armstrong, 2011; Lawrence, 2017; Mannell, 2014; Montesanti et al., 2017). This translation lens allows us to anticipate plural futures for palliative care, beyond the dominant hospice and hospital-based forms (cf. Zaman et al., 2017). We foreground institutional analysis in our study of the translation process.

The unfettered real-time data access that we encountered in Nadia presented an excellent opportunity for an enquiry into translation as an ongoing, dynamic process. The symbolic capital of the imported practice (i.e., what is translated) and global legitimacy of the source context (i.e., from where) are significant during translation (Gouanvic, 2010). However, Kerala's community intervention had been confined primarily within state boundaries, and prior to the training program, most participants at Nadia were unaware of palliative care, or of the Kerala model. Our narrative highlights the processual elements, as actors interpret a health service delivery model developed in another institutional context, encounter local resistance and material challenges and constitute community participation through salient values (here, occupational prestige and camaraderie). In this way, across the study period, we observed over 900 community volunteers mobilize for 'total care' of patients in need of palliative care.

In healthcare translations, we attend to organizations' strategic decisions to engage communities (e.g. Mannell, 2014; Montesanti et al., 2015), particularly by powerful actors such as policy makers, program directors, and managers, without necessarily attending to the

ongoing processes by which participation coheres among members at the frontline. This perhaps arises out of a methodological constraint, where “in vivo and in situ studies of editors or translators based on direct observation in real time” are rare (Zilber, 2006, p. 300). Our processual account delineates how non-elites interpret, give meaning to, transform and adopt the received intervention, and the affective dimensions of this engagement.

Stark economic deprivation and weak institutional histories of civil society organization present organizational challenges. Accordingly, translator’s employment of symbolic power, and vertical solidarities forged among local elites with community members are key mechanisms for resource mobilization and overcoming low organizational legitimacy. Further, in this non-remunerative context, occupational prestige and camaraderie serve as affective mechanisms of institutional work that serve to cohere social participation. Given Nadia’s institutional context, the translated community form materialized as a hybrid form, with vertical and horizontal relational structures. Community interventions, such as the Kerala model, are typified as non-hierarchical settings with bottom-up consensus building (Aveling et al., 2012; Santhosh, 2016; Vijay, 2012). At Nadia, a hybrid community form spearheaded by leaders, may be a contextually appropriate and necessary variation for implementation.

Indeed, Aveling et al. (2017) point to the merit of ‘clinical communities’ that have a blend of a vertical core and horizontal peer linkages. Unlike ‘clinical communities’, Sanjeevani does not have pre-figured structures and activities prior to the translation process. Rather, certain actors, like Mrinal and Sujata, emerge as leaders from the community during translation. Nevertheless, like clinical communities, formulating the Nadia form as one such hybrid of vertical and horizontal linkages, can serve as a prototype for community palliative care interventions in contexts that do not have similar histories of bottom-up organizing like Kerala.

Second, healthcare transfer policies emphasize rational and strategic aspects of evidence-based medical decision-making and implementation frameworks to facilitate desirable health outcomes, resource mobilization, coalition formation, and so on (Kothari and Armstrong, 2011; Montesanti et al., 2017). Foregrounding these rational, cognitive aspects of social life obscures affective elements so integral to caregiving. Our findings point to how, despite the absence of economic incentives, participation is forged around the occupational prestige and camaraderie that members derive. Indeed, research on affects, which draws attention to body, emotions, feelings and passions, delineates how affective labor is productive of socialities, from households and families, to communities and movements (Ahmed, 2004; Hardt, 1999). Future research could shed more light on how affects of prestige, status, camaraderie and conviviality serve as the glue in community-based action in subaltern settings.

Third, we argue that the concept of community is operationalized uncritically in healthcare policies without acknowledging its contested nature (Bertotti et al., 2012; Crow and Allan, 1994; Montesanti et al., 2015, Montesanti et al., 2017). Studies presume communities as already constituted, with shared identities and connectedness, poised to serve as low-cost, resource-effective vehicles for participatory interventions (Lippman et al., 2018; Mansuri and Rao, 2004). We illustrate that ‘community’ cannot be taken as a pre-existing social category in the target field and careful attention must be given to how community participation is mobilized and constituted during translation. Moreover, if organizations are birthed in the institutional legacies of communities (Greve and Rao, 2014), it follows that community forms like Sanjeevani can result in better contextual readiness for future community health interventions.

In sum, our work cautions against simplistic, decontextualized transfer models in global health discourse, and especially those related to palliative care (World Health

Organization, 2014). There have been reservations about the transfer of the Kerala model to other geographies, given its unique institutional context (Sallnow et al., 2010). Indeed, our findings illustrate how transferring a community intervention presents challenges not only across countries but also within India. Our study points to the importance of prospectively analyzing institutional contexts, during healthcare transfer experiments. Such an analysis may help identify important actors like state officials, who in such contexts, may enjoy far greater legitimacy than non-governmental actors.

There is much emphasis on the promise of communities in the 21<sup>st</sup> century (Ahmed and Fortier, 2003). There is also much optimism about the potential of ‘compassionate communities’ to promote new approaches to palliative care (Zaman et al., 2018). We hope our study, by illustrating the challenges and efforts of establishing and maintaining communities, contributes to a meaningful realization of the power contained within them.

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**Table 1. Differences in Institutional Context**

	<b>Kerala</b>	<b>West Bengal</b>
1. Demographic Indicators		
a. Literacy*	93.91%	76.26% - In Nadia - 74.97%
b. Life Expectancy*	73.2% Male 77.6% Female	69.2% Male 72.1% Female
c. Infant Mortality Rate*	12	32
d. Maternal Mortality Ratio*	81	145
e. State Government's per capita health expenditure** (in Rupees, 2009-2010)	499	330
f. % Population below poverty line (2012)***	8%	20%
2. Legal Infrastructure for Palliative Care		
a. Narcotics and Psychotropic Substances Act	Amended in 1999 to ease opioid access for pain relief	Amended in 2014 to ease opioid access for pain relief  - Access on the ground remains limited.  Sanjeevani had no access to morphine.
b. State Government Palliative Care policy	In 2008, Kerala state mandated provision of palliative care at primary health center level	No equivalent policy
3. Voluntary organizations	High density of civil society organizations, including community organizations, co-operatives	Patron-client relations with political parties; political mobilization of communities

\*Census, 2011

\*\*Choudhury and Nath, 2012

\*\*\* World Bank Group, 2012

**Table 2. Translation of Kerala’s Community Form to Nadia.**

	<b>Kerala Community Form</b>	<b>Sanjeevani Community Form</b>
Member Relations	Community ownership	Community participation: combination of hierarchies and horizontal linkages
Organizational Decision-Making	Deliberative, horizontal	Primarily hierarchical – decisions run through physicians, unit coordinators team leaders
Practices - Caregiving	Nurses and volunteer home-care, physician’s home care, physiotherapists	Nurses and volunteer home care, physician’s home care, physiotherapists
Practices - Fund-Raising	Micro-funds from neighborhoods	Big donors – e.g. physicians, politicians.
Operationalizing Total Care’	Social, emotional, spiritual, financial, Medical, bereavement Support, rehabilitation	Social, emotional, spiritual, medical, bereavement support
Patient Categories	Cancer, HIV/AIDS, Chronic renal, respiratory, cardiovascular conditions, Geriatric conditions, Paraplegia, Mental Health	Advanced Cancer, Bedridden patients, Geriatric conditions (over 75 years).
Ties with State Actors	Formal integration into public health system	Patronage/ donor-based relations with local politicians

Sources: Primary data sources; Kumar, 2013; Vijay and Kulkarni, 2012