

Narrative Overview of Translation of a Community Palliative Care Intervention at Nadia district, West Bengal

Sir,
MacCormack^[1] has recommended the collaboration of an anthropologist or rural sociologist with field experience in planning the community participation aspects of healthcare. However, such involvement and its impact have not been captured in the study by Vijay *et al.*, 2018^[2] on their translational study of palliative care intervention in Krishnanagar and surrounding areas at Nadia district, Bengal (although the 2nd author is an anthropologist). This paper provides few other issues which need to be considered for translation of palliative care intervention in Nadia district. Coming to reflexivity, the author is a 6th generation resident of Krishnanagar, Nadia with graduate school training in social sciences. She has been working as a Palliative Care social worker in West Bengal for almost a decade. She has run her

individual project in Nadia district funded by the British Council from 2010-15.

Promoting community participation is a skill which must be taught to community health workers and backed up with support services. The genuine commitment of medical staff to community self-help is crucial to the motivation process. Information about the motivation and strategies taken by the Health professionals to create an effective partnership with community is not available. Motivation within the community quickly breaks down if materials, expertise, and salaries fail to arrive when promised. Information about how the flows of these resources were ascertained is not clear from the paper. Community activities are most successfully promoted with reference to the people's own ideas of health/illness and therefore such information is essential before translation takes

place. Information about the social values of the community has been missing from the paper. In addition, information about common interest of the community (other than the health) is not known. Guidelines for successful community participation include projects undertaken should be ones that the community has identified as a priority; but the project seems to be undertaken at the top-level (MacCormack, 1983).^[1] In the absence of this information, future translators do not get adequate information whether translation is better in divergent communities or in communities with common interests.

The guidelines and checklists for community-based participation and initiatives^[3] should be checked before taking up such community involvement projects.

Information about the mapping of the coverage area of the project and what functionality issues arose in which coverage areas are also not available. The catchment area of the project would have been useful.

Information about the reflexivity of the researchers has been missing from the paper.

The paper shows the strength of the project through the key leadership of District Magistrate, doctors, affiliation of IPM from Kerala. The paper also mentions about the dynamics of empowering women – but we are not sure about the motivation behind it. The paper continues to see the women in career roles. However, this raises an important question about what happens when women are sick. The paper does not provide information about how the model works when women are the care recipients.

Although the paper talks about the challenges in local fund generation, information about the strategies to make the project financially solvent through local fund generation is not available.

Information about the entire schema of the regulatory structure of the palliative care in the community is also not available. For example, information about what happens between the two home visits is not known.

A preliminary inquiry arises about what steps were taken to locally tailor the Kerala model to suit the Nadia characteristics, given the impoverished educational and economic profile of the population and the geographical characteristics of Nadia. For instances – information about what were the changes brought in training, workshop, etc., for the local volunteers, when the population is of poor literacy/or in a setup where narcotic regulations are absent/nonexistent remains untouched. Information about whether pictorial training modules were used for the illiterate volunteers is also not available. We are not sure whether theoretical or practical training was provided and which one is more useful for training which group, such as the drivers. Besides information about the training, modules are also not known. Detailed information about the nature of training,

training module motivation behind the training may provide insights about how to develop strategies and motivate the people/community for community development initiative in resource-constrained settings (here, Nadia is poor regarding financial condition, literacy level and healthcare facility).

We do not wish to question the community-based Palliative Care model of Kerala and the huge discourse it has made globally. However, large-scale investigations on the impact assessment of Kerala model are missing. Besides, micro assessment of Palliative Care in Kerala reveals a dismal picture and alarming gaps in home-based palliative care services^[4] and in policy implementation.^[5] Therefore, it is the moral responsibility of the translator to recognize these gaps before the zeal to translate takes over.

Adequate information about whether the project is running successfully in Nadia, in the absence of policy is unavailable. The study somehow leaves out on updating the present status of the project, i.e., – in 2018. Updated information on the impact and the importance of the translation process in Nadia, would have been significant in enabling the reader to gaze the effectiveness of the process being described, but not otherwise. Although primary assessment data on Nadia is lacking (from other formal sources), informal reports convey a far from the satisfactory picture.

It is not clear how the project aims to sustain, given the fact that most of the translators were not from the community and some even periodically visited; what happens to the project when the outsiders are absent, how the project upholds the motivation level of the participants and the volunteer support, etc., Glaring queries also arise because information about the funding source and source of pharmaceutical supplies/management of the project are missing. In the same vein how was good pharmaceutical management ensured, in the deficiency of adequate literacy levels/financial capacity of the population and also in the absence of tie-up with local hospitals. It seems that huge resources were involved in the transportation of the large number of experts from outside the community.

Many of the challenges involved in understanding communities and mobilizing the community that are discussed in the paper are well known in mainstream sociological literature.

STRENGTHS

1. The issue of translators' symbolic power is reflected in District Magistrate's personality. However when translators who wielded enormous power are not from the community itself, it may adversely affect the entire project implementation (for example, the paper does not provide information about what happened when the District Magistrate got/will get transferred), and moreover, the strategies for sustaining the project in the long run

2. It is known that translation is a contextual process. Contexts and meanings are very important. Further information about the contexts and meaning in the context of Nadia would have been useful for understanding the findings and also for future translators. This paper fails to provide local variation on contexts. Community is not always cohesive, it is documented.

Nisbet^[6] organized The Quest for Community around the ways that power and influence have determined the formation and functions of community. Bernard^[7] believed that as influence is drawn away from a locality, the integration, and cohesion of the community are threatened. Voluntary associations act as intermediates (or mediating structures) between the individual and the state^[8] by increasing influence and fostering a sense of efficacy. Through collective action, they cause the environment to be more responsive to the needs of the individual and the small collectivity. Participation in voluntary associations or in government programs yields a sharing of power that leads to greater “ownership” of the community by the participants, greater satisfaction, and greater cohesion.^[9-11] The concepts of power, influence, and participation as they relate to a sense of community can be seen in the growing neighborhood movement, the strength of labor unions, various social movements, and the Japanese perspective on management. However, the paper does not provide information behind the motivation of the volunteers in Nadia. Information about which groups did not choose to volunteer is also not available. Besides the paper reflects that the retired school teachers, home-makers, young unemployed graduates, and activists were the primary volunteers. We are not sure, whether the first three groups joined the Palliative Care group with the idea of getting employment in some form. We are not clear how the villagers perceived the training to be, whether their belief was supported by the mere presence/support of the DM (a government figure). The fourth group which was involved, i.e.-activists, their motivation is also not clear, like whether they joined to be in the good books of DM, have good contacts with Physicians or to promote their own activism.

The present-day criteria of evaluation of leadership and also for project seem to be a folly, as it focuses on the breadth and not on the depth.

Importance of status markers, camaraderie, and volunteers partnering with local Lions Club, blood donation camp, wheelchair distribution, the need to go beyond health care, or to embed healthcare within the larger social work is appreciated. Fostering important relations with nonhealth organizations, like Lions Club is a appreciable initiative taken in this project. However, it must be remembered that Lions Club membership involves cost and only the affluent are the members of Lions Club. Hence, there is a clear unsaid gap between the givers and recipients. So it remains unclear whether the in-group component of community initiative gets

ingrained in collaborating with Lions Club. However, sharing resources can be a win-win situation for the Lions club and Sanjeevani in papers, but its effectiveness on the society remains questionable.

The study indicates the need for more sociological engagement, for translational projects. This also shows volunteer training should be at what level. Otherwise, the quality the quality of the translational projects remains unanswered in term of its effectiveness to the society.

Overall it is not clear, why Nadia was picked up as the locale for translation. It is true that in resource-constrained districts like Nadia, Palliative Care can actually ambulate the life of the people as it is cost effective. However, the absence of the features to support palliative care (like weak narcotic policy) could be a cause of disaster for translators, as shown in this study. Therefore, the judicious choice of place is crucial in translation.

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Conflicts of interest

There are no conflicts of interest.

Tulika Bhattacharyya

Centre for Research on Ageing, University of Southampton, Southampton, UK

Address for correspondence: Tulika Bhattacharyya,
University of Southampton, Southampton, UK.
E-mail: tb1e17@soton.ac.uk

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