

All Ireland Institute of Hospice and Palliative Care (AIHPC) Special Purpose Education and Practice Fellowship (Institute of Palliative Medicine, Kerala, India) Report

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Location: Institute of Palliative Medicine, Kerala
Theme: Community participation in palliative care development
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Pre-visit Aim and Objectives

My aim was to explore how the Kerala Model might inform strategies to embed palliative care across different patient groups and care settings in the Irish context. I wanted to learn about:

- i. the structures and processes developed to support and expand community participation in palliative care
- ii. the nature of community participation
- iii. the strategies to sustain community participation in palliative care

Objectives

I wanted to understand how the Pain and Palliative Care Society, Kerala

- i. developed and sustained its community participation programme;
- ii. established a support system for palliative care volunteers;
- iii. brought a palliative approach to care within communities;
- iv. expanded its programme to address the needs of other groups of people

Introduction

The importance of situating palliative care within a public health context is increasingly highlighted (Stjernswärd et al., 2007). Within this context, the emergence of compassionate communities promises to go some way in addressing the support needs of people with advanced chronic illnesses and their family caregivers through developing or enhancing social networks and social capital. Within a public health context, social capital contributes to our understanding of the capacities and limitations of social networks for improving health and wellbeing (Lewis et al., 2012). Social capital may also be understood in terms of bonding, bridging and linking. The first refers to close connections involving family and friends and reflects recent palliative care writing (Burns et al., 2011). Bridging social capital refers to looser connections involving community and crosses age,

social identity and ethnic groups (Lin, 2008, Lewis et al., 2012). Linking social capital refers to the capacity of networks to link and build relationships with formal or Government institutions and thus break through traditional barriers and potentially influence policy and practice.

The Kerala Model is more usually viewed as a way forward for palliative care development in low and middle income countries (LMICs). There may also be lessons for high income economies (HICs) in addressing palliative care as a public health issue including the challenges associated with advanced chronic illnesses and the support needs of patients and their informal caregivers. In so doing, it may also be possible to promote debate about the dominant biomedical model of care and potential for a social model to address some of the issues facing palliative care in the future. However, promoting community development approaches needs to be offset against the potential for exploitation of informal caregivers, particularly those who are vulnerable through poverty and who are marginalised (Lewis et al., 2012). Such exploitation may arise as national policies in OECD countries increasingly move towards home-based care while fiscal measures seek to reduce caregiver allowance supports.

I chose Kerala in my application for the Special Purpose Education and Practice Fellowship because of the focus on community participation through Neighbourhood Network for Palliative Care (NNPC). Since its beginnings in 2002, the Kerala Model through the NNPC has achieved 70% palliative care coverage for the region compared with a national average of less than 2%. The population of Kerala is 33 million and 3% of that of India.

Report

During my five weeks there, I attended homecare, outpatients, meetings between volunteers and palliative care nurses, community volunteer functions. I met with individual nurses, doctors, project leaders and support staff and community volunteers. These meetings were an important source for gathering information about the structures and processes of the Kerala Model as a whole. I also had a list of topics for meetings with individual or groups of volunteers. My topics included motivation, role and commitment to volunteering on a weekly basis.

The genesis of the Kerala Model was a response to the inadequacies of a more traditional institution-based palliative model and was founded on the idea of community volunteers. This was not simply a means towards greater utilization of community resources for palliative care delivery. It was rather, a conscious shift from a medical to a social model for palliative care in which communities take ownership by assuming responsibility for identifying and resolving problems through a range of means including generating and accessing resources, and linking with local

Government institutions and politicians. Those volunteers who can commit to a minimum of two hours per week to care of the chronically ill in their community are invited for a 16 hour training programme with a strong emphasis on communication.

Following training, volunteers form groups in their community to support patients with cancer and long term illness, and their families. Support may include basic nursing care, emotional and financial (including food) support, transport to and from clinics, and measures to prevent the family from sinking into greater poverty including support for children's schooling. Since its inception in 2001, the NNPC has grown to include 140 community-owned palliative care programmes with approximately 10,000 patients at any one time and approximately 5,000 volunteers. This work is supported by 50 palliative care physicians and 100 palliative care nurses (Kumar, 2012).

A striking feature of the NNPC is its aim to support patients who are chronically ill and as well as those who are dying. There is no attempt to exclude patients on the basis of proximity to death or diagnosis. The NNPC recognises the relentlessness of the illness burden for patients with advanced chronic illness or disability, and families. In interactions with community volunteers, the overwhelming motivation was deriving meaning from the work and a sense of contributing back to society. Many of the volunteers with whom I spoke were retired and referred to a sense of purpose to their retirement. Others were still working and spoke of undertaking home visits most evenings and during the weekend. Some were business men who had less time for home visits but were actively engaged in problem solving in relation to patient and family needs such as providing transport to hospital or financial support for food.

In addition to these community volunteers, the IPM promotes awareness raising among college students. Students are invited to attend IPM for induction programmes and full volunteer training. I met with a number of groups attending induction, training and train the trainers programmes. They again spoke of enjoying the work and the sense of contribution it brings. One spoke of seeing the effect of the *energy of youth* on people who are isolated from illness. A feature of the awareness raising process is a ready acknowledgement that as little as 5-10% of those who attend will become active volunteers. This is not viewed as a problem since part of the purpose is to simply spread the word and raise broad awareness that may ultimately support the NNPC at local community level.

At meetings between the local community volunteers and the palliative home care nurses, community ownership was evident in the degree of problem solving when nurses raised patient issues. Similarly, the home care nurses took referrals from volunteers for homecare visits.

Fundraising is community based and largely focused on micro financing which is viewed as an important element of community ownership. Volunteers and staff spoke of the importance of establishing ownership so that the rules are set when political engagement began.

Outcomes

In terms of my pre-visit aim and objectives, I have learned what a social model of palliative care means in practical terms and the important nuances this brings to our understanding of social capital. The NNPC addresses bonding, bridging and linking social capital. However, in setting the agenda, the communities are also shaping not just how social networks can be forged to support palliative care but importantly, the development and implementation of policy in relation to care delivery. Support structures and processes for the NNPC are wide ranging including training, regular meetings, and nurturing links with colleges and local Government institutions, and ready and easy access to the home care teams for advice on care.

I was surprised by the interest shown in a reference in my bio to my logotherapy training. The Director asked me to present at a WHO fellowship programme in palliative care. In hindsight, this was not surprising because at its heart, the NNPC is about addressing total pain; emotional and social support that is provided by the volunteers is viewed as core to the palliative care agenda. This is well linked with Logotherapy.

Future

The Institute of Palliative Medicine is currently supporting a number of LMICs to develop palliative care while stressing the importance of local culture and contexts. At the same time, within Kerala, new projects are emerging including mental health support initiatives and a programme to support families of children on cancer treatment. Less understood is the relevance of the Kerala Model to HICs such as Ireland. Continued success of and experiment in the model will depend on the next generation of palliative care leadership in Kerala. However, we do our patients with advanced chronic illness a disservice if we avoid an informed debate about a social model of care and the nuances to social capital that the Kerala model appears to have raised.

Outputs to be delivered as a result of the visit

1. Presentation of report at the AIHPC symposium
2. Presentation of report at the new Palliative Care Education and Practice Development Committee in the School of Nursing and Midwifery, TCD towards:
 - a. Incorporating the theory informing the Kerala Model to palliative care teaching at undergraduate and post graduate levels
 - b. Exploring the potential for a social model in fields such as mental health where there is interest palliative care development for older patients with enduring mental illness or multi-morbidity

3. Report to a small working group that is currently exploring the potential for volunteer input in chronic heart and respiratory failure in a TCD partner hospital
4. Explore opportunities for research and pursue opportunities for academic writing on a social model involving community volunteers in an Irish context. Specifically:
 - a. Explore the potential for a small scale pilot project within an action research framework to examine opportunities for enhancing social capital and networks within a social model context
 - b. Explore opportunities for engaging with emerging debates about social capital in palliative care

Abstracts from: 'Practice development in GI nursing: change and evolution: to be held on Thursday 11 -- Friday 12 November, 2004 at the Telford International Centre. *Gastrointestinal Nursing 2004 Nov; 2(9): 23-38.*

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