

## Addressing the basics of palliative care

Fiona Graham, David Clark

We read with interest Harmala Gupta's observations in which she poses the question 'how basic is palliative care?' (Gupta, 2004). Like her, we attended the international workshop on Community Participation in Palliative Care, which took place in India at Manjeri, Kerala at the end of November 2004 (Figure 1).

The event was organized by the Neighbourhood Network Groups in Palliative Care (NNPC) in association with the Department of Medicine, Medical College, Calicut and the Institute of Palliative Medicine, Calicut. Clearly, for Harmala Gupta it raised some challenging thoughts about the nature of palliative care and the boundaries that surround it. We too felt challenged by the workshop and we have found her article useful in our attempts to clarify some issues, although we reach somewhat different conclusions.

Harmala Gupta makes two key points. First, she highlights the tension that can exist between 'quantity' and 'quality' in palliative care service delivery, and asserts that western palliativists seem to be willing to accept lower standards of care for resource-poor settings than they are in their own, more prosperous, countries. Second, she raises concerns about the types of palliative care work that can reasonably be undertaken by trained volunteers, suggesting that some interventions simply must be left to professionals.

Her overall concern is that in a bid to achieve 'coverage' the NNPC approach to the delivery of palliative care raises the ethical question of whether offering something to a needy population is better than offering nothing at all.

We suggest that Harmala Gupta's questions have to be understood in the wider context of palliative care



Figure 1. Setting out on a home care visit – volunteers of the Areacode Palliative Care Association, Malapurram District, Kerala, India.

development around the world. There have been several triggers to this development visible in different settings (Clark, 2004). In the UK, the early work of Cicely Saunders was clearly a response to the medical neglect of the dying patient. In the USA, hospice initiatives arose out of a sense of frustration with futile medical treatment at the end of life.

In just a few regions (Catalonia, Kerala) can we see evidence of a public health approach that aims at the relief of suffering on a mass scale. Of course, the latter goal, with its concern to achieve coverage, is increasingly the rhetoric of policy in many countries, but it remains hard to find examples of situations in which it has been achieved. In the UK, for instance, where palliative care services are considered to be well developed, they have been heavily criticized for their almost total emphasis on people with cancer, their neglect of those with other conditions, and their unevenly distributed provision (House of Commons Health Committee, 2004). There is a growing view, however, that primary care, delivered by a multidisciplinary team, could be the key to providing palliative care for all.

### Primary care and palliative care

Since the World Health Organization (WHO) Declaration of

Alma-Ata in 1978, health planners in many countries have argued that primary health care involving a high level of community participation is the key to sustainable and effective services that achieve high coverage (WHO, 1979). Curiously, this has not been a factor that has shaped palliative care developments very significantly, even though most of them around the world postdate the WHO Declaration. Indeed, although palliative care claims to 'put the patient at the centre', it has mainly been slow to recognize the importance of community services and public participation, growing instead out of inpatient models of various kinds, in hospice and hospital.

Several tensions can be observed. One well-rehearsed argument is that palliative care services in some settings have become overmedicalized and thereby risk losing touch with the wider goals and purposes of care. Another concern is that a top-down public health model without community participation misses opportunities for public engagement and education. Likewise, where volunteers are heavily involved in hospice and palliative care organizations, they are often confined to specific functional roles and have little influence on service improvement and development. Conversely,

an overdependence on 'lay' perspectives can lead to the marginalization of the professions. It seems to us that these broader issues are related to some of the concerns expressed by Harmala Gupta.

### Our experience of the Manjeri workshops and the work of volunteers

During our time at the Manjeri workshop, we were struck repeatedly by the enthusiasm and commitment of the volunteers involved in the delivery of palliative care in northern Kerala through the NNPC. With a predominance of younger people (and notably men in the 20–30 years age range) there was an obvious contrast with the demographic profile of hospice volunteers in the UK.

The support of some 40 student groups, through programmes called 'palliative care on campus', was also notable. The palpable enthusiasm of the volunteers we met was extremely engaging and may partly explain why western practitioners' views of the arrangements appear, in Harmala Gupta's words, 'really quite forgiving when it comes to India'.

The work of the NNPC has been described in a letter by Suresh Kumar (2004). NNPC is an attempt by a group of doctors and social activists in the South Indian state of Kerala to develop a sustainable community-led service, capable of offering comprehensive long-term

care and palliative care to dispersed and poor communities. The role of the NNPC is essentially that of empowering local communities in this work. In the socioeconomically deprived district of Malappuram (population 4 million) coverage has risen to 70% in 2 years. Early indications suggest that similar results are likely in other districts.

NNPC has achieved the status of a popular movement in health in the area, celebrating a 'Palliative Care Day' in Kerala with great success in January 2004. All the neighbourhood groups under the programme have managed to raise the money needed for the delivery of care locally, through small contributions and support from the local government. NNPC's total expenditure in 2003 was approximately 12 million rupees (US\$ 285 000) out of which US\$ 220 000 was small donations raised locally.

Within the NNPC, those who can spare at least 2 hours each week have a structured course of training consisting of 15 hours of theory and 4 days of clinical supervision. A handbook is provided for the volunteers covering issues such as general patient care, communication, the control of symptoms, spiritual care and the recognition and response to impending death (NNPC, 2004).

Successful completion of the assessment at the end of the course is followed by involvement in an existing team. In areas without a

service, participants are encouraged to form a group of volunteers to identify and support chronically ill people and their families in that locality (Organising Committee, 2004). By such means an extensive network of provision is building up. Rather than an attempt to replace professional involvement these networks supplement it. They are supported by trained doctors and nurses and provide a safety net of social and emotional support and general care in an attempt to realize 'total care' for chronically ill and dying people (Kumar S, 2005, personal communication).

The enthusiasm of the volunteers seems to be equalled by that of the wider local population. The services are supported by donations, many from collection boxes in local shops and businesses and, it seems, even the poorest contribute. In the town of Areacode, Malappuram district, each of the staff working on buses coming into the town contributes a half of one rupee each day to the local NNPC. Some talked of fulfilling a duty to support those less fortunate, of a sense of purpose and self-respect conferred by this, and of a feeling of pride that the community is achieving progress from within. As Dr Kumar remarked to us:

**'it is the community at the centre, the doctors are really on the edges'**

We were struck by the visibility of this community ownership. The conference venue, Manjeri, had large banners over the road advertising the workshop (Figure 2) and the local people were extremely well represented at the events themselves. It would be hard to imagine such scenes at similar events in many other countries.

### What the NNPC programme offers the debate on the nature of palliative care

Was it palliative care that we observed on our field trips with the NNPC? In part this is a question of definition. In the UK there is a much debated distinction between 'specialist' and 'generalist' palliative care. What we observed seemed to



David Clark

Figure 2. Banners in the street. Manjeri, Kerala, November 2004.

fit broadly with generalist palliative care, albeit with a wider range of chronic conditions qualifying the patient for support than is usual in our own country.

The services we observed did have active support from professionals and therefore could be considered multidisciplinary in approach. The volunteers undertook practical tasks, such as helping families wash and change patients and spent time asking about symptoms and other problems.

Like Harmala Gupta, we observed patients who may have benefited from further intervention but, with such a brief visit and with the language difficulties, it was not easy to assess whether these issues had been identified by the team members and were to be followed up. Nevertheless, it is hard to imagine the situation of many of these patients and families without the support they receive from the NNPC. Moreover, the volunteers were engaged in active case-finding. In rural areas where resources are extremely limited, NNPC serves an important role in mobilizing community support.

Home visits from the teams attract attention and this is then used to encourage neighbours to take a greater role in the care of sick, and at times highly dependent, local people. We saw cases of advanced breast and pancreatic cancer and of myeloma. We also visited the homes of men and women paralysed and quadriplegic following work-related accidents in the paddy fields and the coconut groves.

Primary care practitioners in many parts of the world would be quick to take issue with Harmala Gupta's assertion that the control of pain and other symptoms is 'a complex area best left to specialists'. In the UK, for instance, many palliative care patients spend the majority of the final year of life at home, supported by primary health care teams.

With the support of an effective team, such patients can be enabled to live and die at home. Conversely, where patients are unable to stay at home, this is often the result of a

lack of general nursing, medical or social support, rather than the presence of specialist palliative care needs. It is clear that the NNPC model does indeed take its inspiration from the concept of primary care described by the WHO in the Declaration of Alma-Ata (1978), and applies it to palliative care:

**'Primary health care is essential health care based on appropriate and acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain in the spirit of self reliance'**  
(WHO, 1978)

Of course, for some with complex needs, specialist palliative care is necessary. At the moment, however, other than at the inpatient unit of the Institute of Palliative Medicine in Kozikhode (Calicut), which also has an important educational function, this specialist model is less of a priority.

We believe that the NNPC aims to deliver care and support from within the community, which then in turn has the skills to identify when additional help may be needed. We are reminded here of the concept of 'indigenous knowledge' that has captured the imaginations of health care planners in many resource-poor settings in the last few years (see *Box 1* for further information). Indigenous knowledge is the local wisdom that is unique to a society, culture or community. There is lots of evidence from around the world to show that indigenous knowledge is often underused by 'external' professionals, indeed in many places it is being actively eroded. Yet it is an important resource that in the case of the NNPC has been harnessed and exploited, in the best sense.

### Social justice

The NNPC also illustrates that palliative care has a greater significance than its health-care interventions alone. Here we see a popular move-

ment within a specific region, endeavouring to bring together different social initiatives on a platform of social justice and popular reform. We are reminded of Daniel Callahan's observation (2000: 3) that palliative care:

**'is not just a new medical subspecialty but a way of thinking about medicine's goals in a more penetrating way'**

In this sense, NNPC can be viewed as both using and contributing to a wider social capital (Bourdieu, 1983).

### Areas of possible concern

It would be easy to conclude that we considered all was well within the NNPC, but, of course, we had our own concerns. On our field visits we did feel uncomfortable about the invasion of patients' homes by a large group of strangers and worried whether this suggested a lack of empathy or whether it was culturally acceptable.

We wondered how patients were recruited to the service, how much information they were given and whether they consented to the team input. A colleague with a social work background was concerned about patient confidentiality and also sensed reluctance on the part of some staff and volunteers to engage with the often mentioned 'psychosocial support'.

This echoes Harmala Gupta's observation that most of the patients she saw could have benefited from more experienced counselling. Are these very Western concerns? Possibly, but as Harmala Gupta rightly points out, these issues are of concern to all of us in palliative care and it would be wrong to assume that, 'because this is India', they should not be considered.

#### Box 1. Websites on indigenous knowledge

**Indigenous Knowledge and Development Monitor**  
<http://www.nuffic.nl/ciran/ikdm/>

**Indigenous Knowledge WorldWide**  
<http://www.nuffic.nl/ik-pages/ikww/>

### Importance of local awareness

The NNPC is regarded by its proponents as a model for adoption elsewhere in the developing world. There remains a question about how closely it is a product of Kerala's particular history of social reform and public participation. Some colleagues from elsewhere in the subcontinent commented that the initiative could 'only happen in Kerala'. We sensed at times some 'Kerala fatigue' among the participants at the meeting, who were struggling to develop other approaches in different settings.

This emphasizes the importance of awareness of local circumstances. What works in one part of India – or indeed in any other low income country – may not work in another. But, what such regions often have in common is that, while lacking fiscal wealth, they do often have abundant 'people resources' and the NNPC is an example of how these can be harnessed.

Beyond this, there may yet be lessons to be learned by the developed world from this approach – sustainable services for chronically ill and dying people, with public participation leading to a strengthening of communities and the personal growth of individuals within them. In palliative care, in common with other areas of health care, it is becoming increasingly recognized that 'the rich world doesn't have a monopoly on solutions' (Abbasi, 2004).

### Looking to the future

For us, the concerns of Harmala Gupta and some of the other issues

we have touched on here are best addressed through a carefully conducted programme of research. As the workbook for the Manjeri workshop states unequivocally:

**'It is high time that this "phenomenon" is analyzed [and] results evaluated, because it may have lessons for the rest of the developing world'**

(*Organising Committee 2004: 13*)

We agree with this observation. An enquiry of this sort must be approached with an open mind, making use of appropriate research questions and methods. Harmala Gupta's comments highlight the importance of such a study. Our own observations to date suggest that the results could be of enormous importance.

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### Fiona Graham

GP and Palliative Care Physician in Lincolnshire and postgraduate research student at the International Observatory on End of Life Care, Lancaster University, UK

### David Clark

Professor of Medical Sociology, Director of the International Observatory on End of Life Care and of the Institute for Health Research, Lancaster University, UK

### Address for both authors:

International Observatory on End of Life Care, Institute for Health Research, Alexandra Square, Lancaster University, Lancaster LA1 4YT, UK

Correspondence to:

Fiona Graham

Email:

[f.graham1@lancaster.ac.uk](mailto:f.graham1@lancaster.ac.uk)

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Would you like to add to the debate?**

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**Ruth Laughton, Editor, IJPN, MA Healthcare Limited, St Jude's Church,  
Herne Hill, London SE24 0PB, email [ruth@markallengroup.com](mailto:ruth@markallengroup.com)**