

# VIEW FROM THE OBSERVATORY

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## Questions for hospice in resource-poor settings

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*Compassion not combined with wisdom is inefficient in relieving suffering (1).*

The flies show us where the patient is lying. In a dingy hut with just a reed mat to lie on, I watch as the community volunteer greets the painfully thin woman, shaking a hand that can barely be lifted from the blanket. Wide, staring eyes speak volumes: 'I've been waiting for you to come. I'm so scared.' The volunteer pats the patient's hand: 'Come now, you know what happens when you get scared. You know that God is looking after you. You have to pray to him'. The volunteer looks across at me, a bit concerned that she's doing the right thing and helpless that she can't do more than offer her own kindness. She tells the patient that she has brought her some food – nutritional supplements, some cooking oil and some mealie meal. She finds one of the myriad children playing outside and tells her to cook some porridge for the patient later. As we depart, she tells me of the huge numbers of ill and dying in her neighbourhood, but how encouraging it is to be able to do something with her training in palliative care.

This paper identifies some of the questions raised by the need for an appropriate level of palliative care (in quantity and quality) that can realistically be delivered in the face of enormous problems occurring in resource-poor settings. To understand the challenges faced by dying people, their families and those providing palliative care in these environments, I will be drawing on research undertaken for my Masters degree (2) in which I explored how Indian and Zimbabwean hospice workers use the classic British hospice model, my experience as a fieldworker for

the International Observatory on End of Life Care (3), and a growing involvement in questions of international palliative care development.

To contextualise the paper, characteristics of the original British hospice model that are relevant to this paper will be summarised. Observations and reflections on the presence of these in resource-poor settings will follow, with questions raised as to how to ensure effective care for the dying in these environments.

## HOSPICE BACKGROUND

The founder of the modern hospice movement, Dame Cicely Saunders, perceived the increasingly medicalised health system in post-war England as failing to listen to, and meet the needs of, dying patients. She aspired to provide a service outside of the mainstream health system for cancer patients. The hospice movement has been characterised by excellent pain control, compassion and holistic care provided to the dying patient and his family by a multidisciplinary, non-hierarchical team (4). The modern hospice in England is patient-centred, embodies clinical care, education and research and encourages disclosure of diagnosis and expression of feelings (5). This approach recognises the value of relationships between patient, family, hospice professionals and volunteers. Relationships are the conduit for providing care when cure is impossible. Time spent with patients and families to express fears, doubts and feelings is prioritised (4).

This movement provided the foundation for a broad palliative care approach to the dying that could be integrated into mainstream health systems, and a palliative care specialty delivered by trained professional health practitioners. Models of care for the dying have diversified rapidly producing a range of services in the industrialised world that include in-patient units, home-based care, hospital units and day-care centres. In many industrialised countries, accessibility to palliative health care is high. In a study comparing dying patients in Scotland and Kenya, patients in Scotland had access to support and analgesia at home whereas in Kenya, medical and social services were unavailable in rural homes. In Scotland, pain was well-contained, active treatment available if necessary, and specialist palliative care services were available at home as well as in hospital and hospice (6). All this requires a high health worker/patient ratio. Palliative care provided to relatively small numbers of patients by many skilled staff is referred to as 'micro' hospice in this paper.

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There are several examples of emerging palliative care programmes in the non-industrialised world that are designed to respond to the unique characteristics of the communities in which they operate. Characteristically, these services attend to large numbers of dying poor, often due to AIDS and late-referral cancers. For example, the hospital-based Pain and Palliative Care Clinic in Calicut, India has been recognised by the World Health Organization for its pioneering work in bringing pain relief to the poor and needy. In the same district, the people of Mallapuram have developed a system of community-based palliative care through a network of clinics. Both projects draw on volunteers from the community in order to increase coverage and to incorporate 'the concept of voluntary work in health care into the 'social fabric' of the district'(7). The term 'macro' will be applied to hospice and palliative care in these settings indicating low ratios of health workers to patients.

Given the adaptability of the palliative care approach world-wide, the question addressed in this paper is what model of palliative care do we need for resource-poor settings, and what is currently on offer? The original hospice concept that embodies an intensely individualised approach supported by specialist palliative care staff has severe limitations when applied to a resource-poor environment where health workers are usually a scarce resource. Developed to meet the needs of cancer patients, the approach is significantly challenged by the numbers of younger people dying from non-malignant causes. Since AIDS is top of that list in many non-industrialised countries, and carries with it stigmatisation, multiple losses within families and negative economic repercussions, the 'micro' model is sometimes found wanting. In the course of collecting data for the Observatory, I have visited several organisations and services in African countries that provide care for the dying under the auspices of hospice and/or palliative care. Several key issues arise for reflection.

### THE HOSPICE PARADOX

While it is clear that hospice/palliative care has contributed significantly to better care for the dying, it contains an intrinsic paradox. By emphasising listening to the dying, providing skilled care to the whole person and applying specialist knowledge on pain and symptom control, the hospice approach combines complexity and simplicity. On the one hand, its goal is to normalise death as a part of life. It encourages people to discuss death more easily, and to bring care of the dying back into the family rather than have it sequestered in the medical system. Indeed, hospice/palliative care skills imparted to the family are sometimes referred to as 'the simple skills of caring, giving medicine and counselling' (8). Much of what hospice strives for, helping people say goodbye and addressing financial, relationship and practical issues, is 'hardly the stuff of fancy medical technology' (9).

On the other hand, the movement has spawned a host of specialist palliative care practitioners, including doctors, nurses, social workers and counsellors to provide this care. The advent of the term 'specialist palliative care' implies something different from the normality of caring for dying people. Such specialist services may de-skill those who care for dying people as part of their wider duties including relatives and community support groups (10).

### COST OF CARING

Associated with this paradox is the issue of cost. Where skills are specialist, they are usually expensive. Where skills are simplified, costs are reduced assuming the volume of care is the same in both cases. Specialist palliative care (expensive) differs from the palliative care approach (cheap) in terms of cost in that the former can only be practised by professional staff and the latter is usually implemented by the common (wo)man. In resource-poor countries then, is a palliative care approach the only sustainable option? In countries where death is truly part of daily living, where deaths occur regularly and in the public eye, in homes and on streets, and where under-resourced health services place the burden of care on families, neighbours and communities, the issue deserves to be addressed. Rather than palliative care becoming specialised as in the West, the trend in resource-poor countries is to find ways to simplify it and equip lay people with basic palliative care skills to care for the dying in their homes. The question is whether anything is lost in the delivery of care of the dying using a palliative care approach rather than specialist palliative care?

### QUALITY

There is some debate as to whether simplification of palliative care, making it accessible to large numbers, occurs at the expense of quality and wholeness of service. Where resources are limited, 'should one abandon the goal of a Rolls Royce service for a limited number, and aim instead at universal access to effective pain control at least, plus further support if the budget allows?' (11). The maxim appears to be that high quality services can only ever be provided for a few people because they cost more. Lesser services can be spread thinly over greater numbers. The question facing palliative care in non-industrialised countries is whether it is possible to achieve inexpensive, good quality care for many people in resource-poor settings. Moreover, is limited, basic provision of care ultimately acceptable when expectations are low and desperate patients are grateful for anything they receive? In communities where basic foodstuffs are a luxury and running water is unknown, a neighbour who attends to a dying patient with a drink of water may make a significant difference and be as gratefully received as the doctor with a morphine tablet. But is this palliative care and is it

enough? Economic constraints, denial of the disease, social ostracisation, domestic chores and lack of sanitary facilities all add to the burden of the AIDS caregiver. Basic healthcare methods can certainly be imparted to ease the discomfort of the dying, but the possibility of providing quality holistic palliative care at this level remains enormously challenging. Establishing ways of obtaining feedback from such patients on the efficacy of a service is understandably difficult in these circumstances.

## WHO IS PROVIDING PALLIATIVE CARE?

Given the trend in resource-poor countries to spread skills rapidly to community and rural level, who in fact provides palliative care? A core characteristic of good palliative care can be described as having 'a full, vibrant connection with the dying person, who is still regarded as a living person; and that one is attentive to the full range of human experiences that accompany advanced illness, death and bereavement' (12). It seems that in 'macro' settings it is the family, or home-based care provider who has the greatest chance of achieving this, if at all. From my observations, it is increasingly unlikely that palliative care practitioners in resource-poor settings will have such relationships with the dying. In countries such as Zimbabwe, Zambia, and Malawi, for example, palliative care practitioners are increasingly called upon to train other health workers and volunteers, and for themselves to undergo further specialist training, necessary in order to be respected as experts in their countries and, therefore, to advocate confidently for palliative care policies. The same practitioners are regularly invited to international palliative care conferences to pool their knowledge and experiences. Furthermore, they often take a lead role in managing their organisations and doing administrative work. As a result, minimal time is spent with the dying.

## LEARNING ABOUT DYING FROM UNIQUE INDIVIDUALS

The challenge in 'macro hospice' then, given that palliative care specialists may not be in relationship with patients, is how to capture the information that can be learned from the dying in order for palliative care in these settings to develop effectively, rather than to merely manage the numbers? The vast knowledge of hospice/palliative care was born out of many skilled staff listening to small numbers of patients. With overwhelming numbers of patients and few skilled personnel to cope, home-based care services and hospices in these settings have a sense of overwhelming urgency about them. From my experience, there is seldom the opportunity for palliative care workers to sit with and listen to the dying patient. The Zimbabwean respondents in my research would agree with Clark and

Seymour (5) that the individual approach so clearly advocated in Saunders' development of the hospice approach seems at risk of being lost in the overwhelming numbers of the dying in the non-industrialised world. When that is lost, perhaps too is the opportunity for professionals to learn from each patient.

AIDS has brought a real epidemic of death to Africa in particular. In 2003, it was estimated that over 26 million people in sub-Saharan Africa were living with HIV (13). In 2002, 90% of the more than 800,000 children infected that year were in sub-Saharan Africa. When the numbers are so high and the facilities so limited, taking time with the dying to hear their concerns and attend to their total pain may simply not be possible.

## COMPASSION AND KNOWLEDGE

The interviewees in the dissertation research confirmed that family members and community volunteers can certainly be encouraged to provide love, support and informed care to dying people as suggested by Sepulveda *et al.* (14).

*...even...where there isn't a very high education level or where the socio-economic status is low, [families] are quite capable of changing a catheter or even giving an injection if you just show them how to do it and take the time and trouble to do that. (15)*

*...and yes, you need competence...humanity AND...simple ways of relieving discomfort, massage, good mouth care, a sponge soaked in water when you can't use a cup. (16)*

*These home-based care programmes which are mushrooming in Zimbabwe need...standards. Some call themselves home-based care, meanwhile they are a prayer group. So we will say, yes you are doing a good job praying for the sick, but with some training you can improve the quality of care, you can improve your organization. (17)*

Yet there was concern voiced by several respondents that caring for the dying with compassion alone is inadequate and cannot be called palliative care. The body of knowledge that has evolved to ensure pain-free and emotionally restored dying, needs to be applied in tandem with caring. The challenge for hospice/palliative care in resource-poor settings is to find a way to continue learning from the dying to inform good practice, rather than merely providing basic care.

## COMMUNITY

The emphasis in resource poor settings of working 'in the community' implies a sense of community being 'the other',

separated from the professional workers who provide the supervision and training. I also observe a danger in regarding 'community' as something other than the many individual faces it comprises. Perhaps this tendency to use anonymity is emotionally protective and particularly tempting when demands are so high, the conditions so poor, and feelings of helplessness inevitable. My concern is that hospice is likely to lose its focus on the individual voices it must hear if it continues to refer to a 'community' rather than individual patients and families. Listening to the voices of the dying and their families as unique entities, needs to continue to be prioritised if we are to continue learning, researching and developing good clinical practice

### THE MANY HATS OF THE SPECIALIST

Professional health workers in resource-poor settings are often used in areas other than direct patient care. For example, in a country such as Malawi where specialist human resources are limited, about six palliative care professionals serve a country of 11.3 million. Not all the six specialists are even trained in palliative care; some are simply interested and are learning on the job. An estimated 900,000 people aged 15–49 years are infected with HIV/AIDS in Malawi. One in four people are infected in urban areas and one in eight in rural areas. Approximately 87,000 people died from AIDS in 2003 (18). The obvious and inevitable option in this setting is to train volunteer community workers in the basic skills of home-based care so that they can take care of patients within their communities. This resonates with the British hospice model that explicitly included the family within its focus of care, and encouraged voluntarism within its model in order that the community should own the hospice concept (5,19). There are, however, significant obstacles to achieving this in many non-industrialised countries, due to serious limitations in training capacity, support services and medical resources. Those able to impart palliative care skills through training workshops in Malawi are precisely the same health professionals desperately required to provide the only hands-on skilled palliative care in the country. Too few people are available to provide the care itself, along with the training, mentoring and supervision.

### GOVERNMENT SUPPORT

It is clear from various sources that unless care is fully integrated and supported by governments willing to commit to providing good care for the dying, a hospice/palliative care programme at macro levels is unlikely to thrive (20,21). While the early hospice/palliative care movement grew from the dynamism of charismatic individuals, my research provided further evidence of the need for a soci-

etal approach to be taken. This includes Government support, funding and flexible legislation concerning drug and medical supplies. When this is achieved, great progress can be made. The current problems in obtaining basic drug supplies in Zimbabwe and the ability of Indian palliateurs to negotiate for improved morphine supplies are examples of different government approaches. The findings of this research confirmed the most workable combination for the provision of macro palliative care to be a 'top down' (state driven) and a 'bottom up' (community driven) approach as suggested by Stjernsward and Clark (20). Ideally, services need to be available in both urban and rural areas. A recent review of the palliative care needs of rural and urban dwellers highlights increased caregiver burden in rural settings. In addition, unmet information needs and lack of formal palliative care support combine with additional travel costs and family stresses in these areas (22). Palliative care provision has to be integrated into essential primary healthcare services supported by a combination of healthcare professionals. Where integration is ineffective, as in Zimbabwe, provision of care falls to charities and individuals who can never hope to provide adequate care for vast numbers. Palliative care cannot operate in isolation from socio-economic, political and cultural systems. The vulnerability of palliative care programmes in countries affected by social, political and economic turmoil is apparent. Ironically, the disintegration of health, social and economic systems when wider social systems are unstable increases the palliative care needs of the dying and threatens provision of support.

### PSYCHOSOCIAL AND SPIRITUAL CARE

The findings of my research and observations on the ground indicate that as the magnitude of need rises for hospice/palliative care in resource-poor countries there is a risk of decreasing emphasis on psychosocial and spiritual care. Similar results were found in research undertaken in a cross-sectional survey of 66 hospices across the US in a very different context (23). The authors noted in that study that the initial strong psychosocial emphasis in hospice settings in the US has faded with economic tightening and as hospices are increasingly held accountable for how they spend State funds. When funds will only stretch so far, hospice social workers are regarded as 'nice but not necessary' (23). This is mirrored in my research and observations. The Zimbabwean respondents in my research, who had more experience in working with HIV/AIDS than the Indian sample, considered that the sheer weight of numbers of patients rendered comprehensive emotional care impossible to achieve. Simple physical care and community support seemingly has to suffice and psychosocial care becomes seen as a luxury. In several resource-poor countries, I have observed medical care to

be strongly prioritised when resources are short. Emotional and spiritual support is usually left to the family and seldom explored in any depth by hospice workers. Furthermore, psychosocial practitioners are a scarce resource in this environment. In the Kenya/Scotland comparative study (6), it was concluded that family and local religious communities do meet psychosocial and spiritual end of life needs in non-industrialised countries.

My observations in the field highlight that good counselling is a rarity within palliative care for adults and, more worryingly so, for children. Many services in Africa provide a day-care centre for children who have been orphaned by AIDS, and for children themselves infected by the virus. Emphasis is unfailingly on hygiene, good nutrition and education, all of which are indeed lacking in their own homes. What is significant, however, is the absence of skilled social workers, counsellors and health workers equipped to communicate with dying and bereaved children. Many organisations providing end-of-life care in Africa are faith based. While the standard religious support provided by these services may suit some, what impact does this have in terms of exploration and support of individual spiritual needs? There is little evidence on the ground that healthcare policies in these countries do in fact commit to developing counselling and spiritual resources, despite the assurance of a commitment to the holistic nature of palliative care embedded in the most recent definition from the World Health Organization: (24)

*Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*

WHO/UNAIDS acknowledge that insufficient remuneration and support for care professionals are major barriers to implementing effective components of AIDS care and support (25). My research and observations would add that this applies particularly to psychosocial and spiritual professionals.

## CONCLUSIONS

The issue of ensuring and sustaining quality of macro palliative care deserves further research. We need to explore whether by providing 'simplified palliative care' we are sacrificing quality to the extent that we are offering an unsatisfactory level of care, albeit some care to large numbers of people. Developing research methods to establish this will be difficult given the gratitude for any comforts in resource-poor settings.

It is clear that there are strengths on which we can draw in these countries despite the many hardships. My research sought the voices of those providing care. What I observed on the ground is that there is not a great deal of listening to the dying. Similar empirical work needs to extend to those who receive hospice/palliative care. Patients and their families need to be heard as to what constitutes a good death, and whether 'macro' palliative care as it is practised now may be considered a 'good enough' death (5,9). The challenge ahead lies in finding innovative, sensitive ways to hear what dying is like for those in receipt of 'macro' palliative care.

Consideration needs to be given to applying the lessons learned from the simplification of palliative care in 'macro' hospice to 'micro' hospice conditions. Exploring ways of drawing on the capacities of the patient, family, communities and faith organisations to meet some of the needs of the dying, can be achieved by studying macro palliative care programmes. The responses of individuals and families affected by dying, never easy, have formed the core of hospice knowledge. Knowledge gained from those coping with multitudinous deaths under trying circumstances, were it to be harnessed, could well prove inspirational.

## REFERENCES

1. Stjernsward J. Cited in Burn G, Bowring G. India. In: Ferrell B, Coyle N. (eds) *Textbook of Palliative Nursing*. New York: Oxford University Press, 2001;739.
2. Hunt J. From micro to macro. A comparative analysis of views on how India and Zimbabwe use the British hospice model. Unpublished dissertation for MA in Death and Society, Reading University, 2003.
3. <[www.eolc-observatory.net](http://www.eolc-observatory.net)>.
4. Hockley J. The evolution of the hospice approach. In: Clark D, Hockley J, Ahmedzai S. (eds) *New Themes in Palliative Care*. Buckingham: Open University Press, 1997.
5. Clark D, Seymour J. *Reflections on Palliative Care*. Buckingham: Open University Press, 1999.
6. Murray S, Grant E, Grant A, Kendall M. Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers. *BMJ* 2003;**326**,368–71.
7. Majeed A, Basheer K, Numpeli M, Mol S, Kumar S. The neighbourhood network – a social experiment. *Hospice Inform Bull* 2002;**1**:7–8.
8. Reubens C. Summer in Calicut. *Hospice Inform Bull* 2002;**1**:8.
9. Clark J. Patient centred death. *BMJ* 2003;**327**:174.
10. Clark D, Hockley J, Ahmedzai S. Series Editors Preface. In: Clark D, Hockley J, Ahmedzai S. (eds)

- New Themes in Palliative Care*. Buckingham: Open University Press, 1997.
11. Farsides C, Garrard E. Resource allocation and palliative care. In: Clark D, Hockley J, Ahmedzai S. (eds) *New Themes in Palliative Care*. Buckingham: Open University Press, 1997;54.
  12. Barnard, D. Palliative care: whole-person care of the dying patient. *World Anaesth* 1998;**2**:1.
  13. UNAIDS fact sheet, December 2003. [www.unaids.org](http://www.unaids.org) (accessed 25/04/04).
  14. Sepulveda C, Habiyambere V, Amandua J, Borok M, Kikule E, Mudanga B *et al*. Quality care at the end of life in Africa. *BMJ* 2003;**327**: 209–13.
  15. Harmala Gupta (interviewed 2003). In: Hunt J. From micro to macro. A comparative analysis of views on how India and Zimbabwe use the British hospice model. Unpublished dissertation for MA in Death and Society, Reading University, 2003;62.
  16. Gilly Burn (interviewed 2003). In: Hunt J. From micro to macro. A comparative analysis of views on how India and Zimbabwe use the British hospice model. Unpublished dissertation for MA in Death and Society, Reading University, 2003;77.
  17. Eunice Garanganga (interviewed 2003). In: Hunt J. From micro to macro. A comparative analysis of views on how India and Zimbabwe use the British hospice model. Unpublished dissertation for MA in Death and Society, Reading University, 2003;74.
  18. Laurance J. Promise of drugs gives Malawians fresh hope – and a reason to get tested for HIV. 2004 [http://news.independent.co.uk/world/science\\_medical/story.jsp?story=492799](http://news.independent.co.uk/world/science_medical/story.jsp?story=492799).
  19. Saunders C. Personal communication. 2003.
  20. Stjernsward J, Clark D. Palliative medicine – a global perspective. In: Doyle D, Hanks G, Cherney N, Calman K. (eds) *Oxford Textbook of Palliative Medicine*, 3rd edn. Oxford: Oxford University Press, 2003.
  21. Wright M, Clark D. Hospice care in Russia. *Prog Palliat Care* 2004;**12**:27–9.
  22. Hughes P, Ingleton C, Noble B, Clark D. Providing cancer and palliative care in rural areas: a review of patient and carer needs. *J Palliat Care* 2004;**20**:44–9.
  23. Reese D, Raymer M. Relationships between social work involvement and hospice outcomes: results of the National Hospice Social Work Survey. *Social Work* 2004;**49**:415–22.
  24. Sepulveda C, Marlin A, Yoshida T, Ullrich A. Palliative care: the World Health Organization's global perspective. *J Pain Symptom Manage* 2002;**24**:91–6.
  25. Foley K, Aulino F, Stjernsward J. Palliative care in resource-poor settings. In: O'Neill J, Selwyn P, Schiltinger H. (eds) *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS*. Rockville, MD: HIV/AIDS Bureau, Health Resources and Services Administration, US Department of Health and Human Services, 2003.