Faith Mwangi-Powell

Dr Faith Mwangi-Powell is currently the Executive Director of the African Palliative Care Association (APCA), a post she has held since joining in January 2005.

Dr Mwangi-Powell is a member of the board of directors for the International Association for Hospice and Palliative Care (IAHPC) and the Foundation for Hospices in Sub-Saharan Africa (FHSSA) and a member of the advocacy committee for the Worldwide Palliative Care Alliance (WPCA). Prior to the APCA, Faith worked for two and a half years with the Diana, Princess of Wales Memorial Fund, London, UK as an International Advocacy Officer for Palliative Care.

Connecting diversities to scale up palliative care in Africa

Globally, approximately 56 million people die each year. Moreover, 42 million currently live with HIV/AIDS, and there are 15.3 million new cancer cases per annum. An estimated 60% of such people would benefit from palliative care. However, scaling up palliative care services to meet this need has numerous challenges that have worldwide applicability, including: limited workforce capacity; lack of policy integration; unavailability of effective pain relieving medication; lack of research evidence; low public awareness; uncommitted governments; the lack of funding; entrenched attitudes within the medical profession; cultural taboos surrounding death and the disclosure of diagnosis; and the absence of a consensus that regards palliative care a basic human right.

In Africa, these challenges are compounded by the high disease burden and poverty. It is against this backdrop that this presentation will provide an overview of palliative care development across Africa. Following a description of the existing levels of palliative care need, it will explore the different service models that have been developed to address that need. It will be contended that connecting the diversities in service provision, whereby achievements and successes are replicated and weaknesses identified, is essential to optimise service delivery across the continent to those in need.

One of the ways in which these connections can be forged is through differing partnership models: both at the micro (ie peer-to-peer) and the macro (ie provider-to-provider, organisation-to-organisation, both nationally and internationally) level. Drawing upon the experiences of the African Palliative Care Association, this presentation will review such collaborative partnerships, highlighting their value in collectively beginning to address the need for palliative care development, and outlining some of the challenges entailed in ensuring they function successfully ■

Barbara Monroe

Barbara has been a social worker for over 30 years. She joined St Christopher's Hospice in 1987 and became Chief Executive in 2000. She is also Chair of the national Childhood Bereavement Network. She has written extensively about the psychosocial aspect.

Resilience and palliative care

Resilience is receiving increasing research attention as we seek to explain the variety and complexities of human response to difficult circumstances and the recent understanding that many more individuals than initially thought can continue to thrive despite adverse experiences and compounding risk factors. Resilience is not just about re-forming but about the possibility of growth. It offers a unifying concept to sustain the most significant understandings of four decades of palliative care and incorporate more effective investment in community and public health approaches. This integration is vital if we are to reconcile the tension between the rhetoric of choice and equity in end-of-life care and the demands of rising healthcare expectations in aging populations with increasingly limited professional and financial resources. These Western world challenges are compounded by the huge needs of resource-poor countries.

Resilience is inextricably linked to risk in an interactive process occurring over time and influenced by individual and family variables, social context and social structure. Resilience demands a more sophisticated assessment, recognising that many of these variables are cross-cutting and can be positive or negative in impact. It is important for the future development of end-of-life care that health and social care issues remain integrated. A return to the privileging of a narrow medical definition of palliative care is presaged, 'The central aspect of palliative care is symptom control delivered humanely with adequate information… undue emphasis on attending to families is demanding of resources which might be better devoted to a wider population of patients' (Randall and Downie 2006). Fortunately some of the economic realities of modern healthcare are drivers in a more positive direction. A recent systematic review of factors influencing death at home in terminally ill patients with cancer emphasises the need to explore family support and empowerment and the role of prevention and public education (Gomes and Higginson, *BMJ* 2006). Palliative care has often been slow to respond to the challenges of disadvantage and exclusion. If it is to do so it must not lose the founding ethos of hospices which sought to empower and to promote strengths and resources.

Analysis of a series of ten study days on resilience in palliative care held at St Christopher's in 2005 revealed key themes: secure attachments, meaning and sense, hope, coherence, creativity, good memories, public education and community support, cultural awareness, internal locus of control, wellbeing, self-esteem, one supportive person and learned optimism. Insights from the field of bereavement underline the importance of balancing vulnerability and health promotion. Evidence supports the beneficial power of narrative in meaning making and the integration of difficult experiences. Studies on 'hope' emphasise the value of reminiscence therapy, humour and the nurturing of independence. Creative therapies can also increase the resources of individuals for use at time of threat. Resilience work supports the concept of brief, focused, cost-effective interventions designed to avoid pathologising and to boost confidence, coping and action. Examples include cognitive behavioural therapy and Kissane's family-focused grief therapy. A clearer understanding of the neurobiological basis of behaviour and its links to resilience is developing.

Palliative care must work in partnership with the communities in which people live to change attitudes and empower them to respond supportively. Canada and Australia have developed government and workplace initiatives to support carers and the terminally ill. Palliative care already uses professional education to extend its messages beyond its immediate sector. School-linked programmes and attempts at wider public education are emerging. Social marketing and information strategies will become more important as we try to find the right balance between expert professional interventions and general loss education. Public receptiveness to internet based resources points to some of the possibilities. Studies of user involvement and group work in palliative care demonstrate the positive therapeutic impact of engagement and increased social connectedness. The future will hold new forms of mutual help groups and volunteering.

The concept of resilience makes it clear that individual factors such as a sense of agency and seeing the world as understandable must be linked to positive family, community and cultural resources, values and connections. Efforts to improve individual welfare cannot alone meet the aspirations of society in relation to high quality, cost-effective and equitable care for all dying people. The West has much to learn from the community-funded and volunteer-supported programmes in resource-poor countries ■

Dr Peter Lawlor

Dr Lawlor worked with the Edmonton Regional Palliative Care Program prior to returning to Dublin in 2004 as a consultant at Our Lady's Hospice and St James's Hospital. He holds an adjunct Associate Professor appointment in Palliative Care Medicine at the University of Alberta.

Hydration practice: attitudes and evidence

Hydration in end-of-life care is often viewed as signifying the essence of compassionate care. Much of the literature on artificial hydration (AH) relates to rhetorical arguments and studies of limited scientific rigour. Much of the controversy has arisen from diametrically opposed viewpoints: the hydrate "all" approach of the relatively more aggressive biomedical model of care, versus the more conservative hydrate "none" approach of the more traditional hospice model of care.

The opposing views are reflected by the great variation in the practice of AH. Variation occurs in the proportion of patients who receive AH in different cultural settings and care locations. Variation has also been noted in the volumes of fluid administered and in the route used for hydration administration. It has been suggested that patients will often defer to their physicians in the decision-making process, and ultimately do what the physician suggests.

Hypovolaemia and dehydration are fluid deficit states. In hypovolaemia, the fluid deficit is in the intravascular volume, which can be iso-, hypo-, or hypertonic depending on the proportion of water and solute that is lost. In dehydration, there is a loss of total body water, which invariably comes from the intracellular department. Dehydration is associated with hypernatraemia, whereas hypovolaemia can be associated with iso-, hypo-, or hypertnatraemia. Fluid deficits can arise due to decreased intake, increased loss, or both. It should be remembered that fluid loss can occur with "third spacing" of fluid, as occurs in ascites. Physiological changes occur with aging, including a reduced proportion of total body mass due to water, a possible reduction in thirst response to dehydration, and a decrease in renal response to intravascular volume changes. Many of the classical symptoms and signs of fluid deficit are unreliable in the elderly and in cancer patients.

The identification of clinical outcome measures and biochemical indices that truly reflect hydration status has been a major research challenge. Only six studies met the inclusion criteria of a systematic review, in which no conclusion could be drawn regarding benefit. The studies that have examined dry mouth or thirst suggest that it occurs in 61–87% of patients receiving end-of-life care. However, confounding variables such as anticholinergic or psychotropic medication use, stomatitis, and mouth breathing can create difficulty in interpreting study findings. The biochemical indices of hydration have largely proved inconsistent in their reflection of hydration status. One study found that atrial natriuretic peptide levels may prove useful in determining hydration status.

To date there is only one published randomised controlled trial that examined hydration benefits in advanced cancer patients. It demonstrated a significant improvement in the sedation and myoclonus scores in the hydration treatment group. The authors of this study reported patient accrual difficulties due to the frequent co-occurrence of dehydration signs and cognitive deficit, thereby creating difficulties with obtaining consent at study entry.

Studies of delirium, a multifaceted syndrome that is often potentially reversible, have demonstrated some conflicting results. In one study dehydration was identified as a covariate significantly associated with delirium reversibility. A Japanese study demonstrated that dehydration occurs in association with delirium but not necessary with reversibility. Most opioids and their metabolites are renally eliminated. Demonstration of opioid toxicity in association with elevated levels of opioid metabolites has been inconsistent, except in the case of renal impairment. Given that a fluid deficit state may progress inexorably to the state of prerenal renal impairment, it seems logical at least to consider AH in patients on opioids who are fluid deficient, or at risk of fluid deficit, in order to prevent prerenal renal impairment.

In the decision-making process on AH we need to consider: the true hydration status of the patient, the complications and symptom burden occurring with the fluid deficit state versus AH; the patient's prognosis and decision-making capacity; knowledge, attitudes, beliefs and wishes, of patients, their families or proxies, and the multidisciplinary team regarding AH; concomitant use of sedatives and withholding or withdrawal of AH; the assessment of delirium reversibility. Ultimately, the best ethical and evidence based practice will involve an individualised approach to AH. A timed trial may be considered. Education and support is essential for relatives, who should receive clear and consistent communication from the multidisciplinary team ■