

Death and development in the Pacific

By Jo Spratt

In any Pacific country it doesn't take long before you meet people who are caring for dying loved ones at home, with very little support. Immobility. Pain. Incontinence. The fear, and often shame, associated with terminal illness and a deteriorating body. These are some of life's biggest challenges anywhere, let

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alone in a remote village where water and electricity aren't within arm's reach. These challenges raise important questions about what can be done to assist, and whether aid and development efforts can make space for death.

These questions are increasingly relevant across the developing world, as populations age, and non-communicable diseases become more prevalent. Across the Pacific, non-communicable diseases already cause 75 per cent of all deaths, with indications this is rising (see this Pacific Framework for the Prevention and Control of NCDs). Acoss the world, cardiovascular diseases, cancer, chronic respiratory diseases, AIDS, and diabetes are the dominant diseases for which adults need palliative care (a sub-set of end of life care measured by the need for pain control) (The Global Atlas of Palliative Care). End of life care is also necessary for people and families enduring conditions such as dementia, Alzheimers and Parkinsons.

Development efforts, particularly aid, are all about saving and improving lives. The metrics account for lives saved, deaths averted, immunisations administered, water-wells built and children in schools. In relation to non-communicable diseases, both the Pacific Framework and the Global Action Plan indicators are all about reducing risk factors and disease burden prevalence. This focus on prevention is crucial. In resource-poor environments, Pacific governments are already spending up to 60 per cent of their health care budgets on expensive tertiary care (Pacific Framework). These diseases are preventable and we must prevent them. (More analysis here and here.)

Yet it will take time for prevention efforts to have an effect, and even when (or if) they do, people will continue to die from non-communicable diseases. This will be exacerbated by increasingly <u>aging</u> populations, who, even without non-communicable diseases, also have particular end of life needs themselves.

Ultimately, after a certain point, some diseases have no cure. Yet we have the knowledge and technology to support people to live as well as possible up until

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the moment of death. End of life care accepts death as a normal life process, and provides holistic support to dying individuals and their families, to prevent and relieve physical, psychosocial, emotional and spiritual suffering. Given the fact we all die, and that the statistics show that many Pacific Islanders will die slowly (as a result of such factors as high blood glucose and high blood pressure), end of life care is an area that cannot be overlooked.

In the Pacific, this is an issue that few governments or aid agencies have turned their attention to. The Global Atlas of Palliative Care updated and refined a 2006 study that had analysed all countries and placed them in one of four categories. In the 2011 updated version, the majority of Pacific Island Countries and Territories (PICTs) were categorised as undertaking no known palliative care activities (category 1). Fiji and Papua New Guinea were placed in category 2, with capacity building activities underway to develop palliative care services. I suspect PNG should actually be in category 3a, which involves isolated palliative care provision, due to efforts there to care for people dying of AIDS. (The study's authors note challenges with categorising countries.) However, the only PICT that is included in this category is Niue, which had improved its position from the 2006 study. Category 3b includes countries that offer generalised palliative care provision, while countries in category 4a and 4b are those where palliative care services are becoming, or already are, fully integrated into mainstream health services. No PICT falls into these categories.

Given the significant challenges for PICT governments in preventing non-communicable diseases, I'm wary of putting forward a shopping list of recommendations for governments to undertake: there is not enough resources available for prevention, let alone end of life care. But this is an area where families need help: globally, approximately 37 per cent (p. 74) of all deaths from all causes will need palliative care alone. This is likely to be a low estimate in the PICTs given the high prevalence of mortality risks. So what could be done?

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I don't have any radical solutions and in light of the suffering terminal illness can bring, my suggestion seems inadequate. Yet sustainable change only comes from understanding the context and carefully devising appropriate responses. Therefore, a useful place to begin is to understand the current situation. Pacific-specific research into the existing needs and services will enable a robust assessment of potential next steps. Currently, Pacific data is aggregated with Asian country data, which obscures Pacific issues. Families and communities are already providing end of life care and will have developed approaches that we can learn from, and build on. No doubt faith-based services, such as those provided by Churches, will also be active in this area and have important insights to share. Research could also examine the presence of laws and policies, standards, health workforce and public education activities, and the consumption of morphine-equivalent strong opiod pain relief (which is actually an 'extra' indicator in the Global Action Plan on Non-Communicable Diseases). This is no small task. People don't like talking about death: for many it speaks of defeat and failure.

Done well, this is where research can make an extra contribution through instigating conversations about an overlooked, and often taboo, subject. Currently family (often women) care for people who are dying, hidden away in homes and villages, with tentative or non-existant links to formal health care services. Simply talking about end of life care can help policy-makers, health professionals and others in positions of power understand what these families experience, and that there are ways to ease suffering and instill peace and hope, even at the time of death.

Development is about improving the quality of life and improving the quality of dying is an integral component of a better life. End of life care, therefore, is a crucial undertaking for aid and development efforts. While governments focus on preventative activities, there is space for others, such as non-government and faith-based organisations, to work alongside to improve end of life care for those where prevention comes too late.



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