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Cultural considerations in planning palliative and end of life care

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Ending life with dignity, with freedom from pain and with appropriate social, psychological, spiritual and medical support are widely accepted as attributes of good palliative care - but the manner in which this can be achieved certainly varies enormously across cultures, jurisdictions and settings. There are many features to the related debates. Efforts to extend quality end of life care are underway in many countries, but are often under-resourced and lack coverage. Moreover, we still have limited agreement on just how these efforts might be more successful. There are examples from many societies of the apparent failure to care for older people effectively and adequately as they face death - at home, in hospitals, in care homes, prisons and other institutional settings. As the effects of population ageing are felt and as the incidence and prevalence of dementia increase, these challenges will grow. There are also special requirements arising from the pandemic of AIDs-related deaths and from increasing mortality associated with cancer in the developing world. Recently there has been debate about whether palliative care can or should be the answer to good end of life care in all contexts. Some arguments, particularly from the rich world, propose wider access to assisted dying and the legalisation of euthanasia, to extend 'choice' at the end of life and promote autonomy. Others seek not elite dying for the few, but palliative care principles embedded across the health and social care system, thereby maximising benefits for the greatest number. Some positions revolve around the need to build community resilience in the face of ageing, dying and death, drawing on perspectives from health promotion and public health to develop strategies for intervention.

It is not uncommon in these debates to come across ritualistic, even hollow-sounding, exhortations that we must promote care which draws on 'indigenous knowledge', that is 'culturally appropriate', or even 'culturally sensitive'. I understand culture to consist of the beliefs, values, behaviours, and dispositions that exist among groups in society. Culture also has a material dimension – in objects, manufactured things, and practical inventions. Through culture, we define who we are, to what extent we conform to shared values, and how we contribute to community and society. Although palliative care makes universal and global cultural claims on behalf of all people with life limiting conditions, there has long been a recognition that it must be rooted in specific cultural contexts if it is to thrive and be effective. There are two dimensions to this.

First, there is the particular recognition that patients and families 'have a culture'. Working with and understanding this culture is seen as key to successful care giving. Recently there have been efforts to suggest that our understanding of culture, seen in this way, should be nuanced and sensitive – and alert to heterogeneity within it. Members of a cultural group may not share the same beliefs about a given phenomenon – for example, as to whether a dying person should be told of their

condition¹. This is a welcome advance on the 'checklist' approach to patients' culture that has been so much criticised in the past.

Second, there is the recognition that palliative and end of life care systems, services and those who deliver them – are also possessed of 'culture'. By this we mean that palliative care delivers a culture as part of its activity – it perpetuates and maintains the values and beliefs of those who work within it, those who support it, and those contribute to its development. Palliative care teaching, research, advocacy, fundraising, publications and presentations, conferences and seminars – are all cultural manifestations. For practitioners, understanding one's place in that culture, requires what sociologists call 'reflexivity' - an ability to see how and why one acts upon a particular situation and at the same time how and why one is acted upon in the process.

In this issue of the journal we can see examples of papers that address 'culture' from both of these perspectives – attending to the culture of patients and service users as well as to the culture of professionals and service providers and placing this in a societal context. They make for interesting reading.

Teng, Chan and Cheng take the first approach. They conducted a systematic review to investigate cultural differences in Western and Asian patient-perceived barriers to managing cancer pain. Asian patients were found to perceive greater barriers than were Western patients, especially for concerns relating to greater pain being evidence of disease progression, fear of developing tolerance and fatalism that cancer pain is inevitable. The differences, drawn from data on 3428 study participants were striking and raise some important questions about how such barriers can be overcome. Mo and colleagues used a survey method to look at the place of autonomy in end of life decision making in Korea. They acknowledge that conflicting views on the issue of patient autonomy have become an important source of tensions between patients, families and medical staff in Asian countries. The results were not clear cut. 70% of patients wanted to be involved in making decisions about their care and 93% preferred to be informed about their situation. But at the same time 30% wished to leave decision making to others and just 53% expressed a preference to know their diagnosis. These authors, like Cherny, argue for the 'nuanced' approach to dealing with cultural values and caution against over deterministic views about the relations between 'autonomy' and 'culture'.

Three other papers touch on the second approach to culture – raising questions about beliefs, values and practices in shaping the delivery of hospice and palliative care. Gott and colleagues used interviews and naturally occurring focus groups to explore the roles and understandings of generalist and specialist providers of palliative care, working in both England and New Zealand. They highlight the gap between palliative care policies imposed at the macro level and their consequences in the realm of practice. In both countries there were differences in the cultures associated with 'palliative' and 'end of life' care – and considerable uncertainties among generalists about their responsibilities in these areas. Daveson and colleagues also made use of the comparative method to study the views of European and African nurses on the use of outcome measurements in palliative care – using an electronic survey method. Surprisingly, they have little to say about cultural factors associated with the geographic spread of their sample, though they do highlight differences in the cultures of professional care. Doctors were much more likely than nurses to be currently using an outcome measure and far less likely to have never considered using one. A fascinating study by Loiselle and Sterling, using small group and individual interviews, focussed on a particular model of palliative care

delivery developed in Bangalore, India and sought to understand health workers' views about death and dying. The findings show how 'personal views, socio-economic status, beliefs and values, occupational experience, and workplace interventions interact to shape "worldviews" about death and dying'. This study has much to say about the notion of 'hardening' when workers are exposed repeatedly to the deaths of patients. It also draws attention to some of the challenges involved in providing opportunities to young women from impoverished backgrounds through hospice work, for which they might then be unprepared emotionally. Cultures of care are all pervasive in this paper, and the analysis is the richer for it.

The studies reported here give at least some encouragement to those who would like to see more emphasis on the cultural dimensions of palliative care. They are striking in their use of differing methods and in their varying degrees of sophistication about 'culture'. In the future as resources shrink and demand increases, it seems likely that cultural factors are going to play just as strong a part in shaping end of life care around the world as will policies, professional ideologies and service configurations. Putting culture at the centre of palliative care will be a key determinant of efficacy and sustainability.

¹ Cherny, N Controversies in oncologist-patient communication: a nuanced approach to autonomy, culture and paternalism. *Oncology* 26(1): 37-41, 2012.