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Losing The Public Understanding Of Dying: Retaining Old Wisdom As Medicine Advances

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Abstract

Public understanding of the natural process of dying is becoming lost in communities where death in hospital has become the norm. Misinterpreting the physiological process of dying as symptoms of distress can further undermine witnesses' understanding. Fears about dying remain unspoken, and contribute to patients or families requesting increasingly hopeless, expensive medical interventions that delay but do not prevent death.

India might preserve public understanding of dying by education of clinicians, future clinicians in training, and of non-medical advisers who support people at the end of life, to be able to recognise and describe dying, and to provide information to patients and family questions about this natural process.

Key words: dying, death, palliative care, public understanding, futility, advance care planning, quality of life

After 30 years in the practice of Palliative Medicine in the UK the author was disappointed to find that community understanding of dying remained vague, still shrouded in fear and superstition, a subject unsuitable for public discussion. In the three decades since the Association for Palliative Medicine was founded in 1986, the specialty of Palliative medicine has been recognised by the Royal Colleges of Physicians across Britain and Ireland; hundreds of doctors have completed higher professional training to become consultant palliative physicians; every UK hospital has access to a palliative care team; nursing competencies in specialist palliative care have been described; there are specialist palliative care teams offering clinical assessment and advice to GPs and community nursing teams; there are hospices the length and breadth of the country; there are academic Departments of Palliative Medicine in Universities and medical schools. And yet how we die remains unknown by the public we serve.

How has this happened? And can India take steps to avoid the same difficulty?

Until the 1950s, death in the UK was usually at home. Before the foundation of the National Health Service in 1948, only the wealthy could afford hospital care. With access to the new NHS further building upon improvements in public health thanks to better sanitation and housing conditions, the major causes of death in UK adults changed from TB and other infections to cardiovascular diseases

and malignancies.

Over the second half of the 20th century, people who would previously have died in their prime could be taken to hospital where they would benefit from newly-available antibiotics, better anaesthetics making possible more extensive surgery, or more effective anti-cancer treatments; the most ill people could receive organ support on Intensive Care Units or even organ transplantation; new treatments offered the prospect of recovery from conditions that would have proved fatal only a few years earlier. Now they were no longer caring for relatives dying at home in childhood, young adulthood or before the end of their working lives, British people became unfamiliar with the progression of illness towards death, and with the process of dying itself.

Dying, rather than being simply the inevitable outcome of life, has become an ‘enemy’: a medical outcome to be avoided at all costs; a failure. Escalation of therapeutic interventions intended to preserve life segues invisibly into a danse macabre in which dying is medically prolonged but not avoided. ‘He died fighting,’ report the deceased’s family. ‘Do everything!’ plead the patient’s children. No matter that she is elderly with multiple co-morbidities and a very poor quality of life; death is the enemy. But is it?

In 2015 for the first time, dementia became the commonest cause of death in women in England aged over 80 [1]. Medical advances have changed life expectancy so that UK girl babies born in 2018 have a life expectancy of 82.9 years, 79.3 years for boys [2]. Annual incidence of dementia is rising, and the ‘dementia epidemic’ in the UK has been a wake-up call that quality of life, and not only length of life, is an important factor to be considered by patients, families and medical advisers when planning and providing medical care.

We have been here before. In response to the observation that anti-cancer treatments, whilst undoubtedly extending the length of many patients’ lives, had troublesome side effects which impacted severely the quality of their final weeks and months of life, Dame Cicely Saunders founded the first ‘modern’ hospice, St Christopher’s, in the 1960s. Here, she assembled a clinical team who valued quality of life ‘in the round.’ Their vision was to enable whole-person care: physical symptom relief; emotional well being; spiritual calm; and attention to the social aspects of each patient’s individual family, friendships and role. Dying was not their enemy: living miserably, and dying uncomfortably, were the enemies they chose to tackle.

Those principles of holistic care, i.e. physical, emotional, spiritual and social domains, remain the bedrock of modern palliative care. The bio-psycho-social model of wellness is becoming better understood: the psychological, hormonal, immunological and neurological sequelae of distress in one domain that cause or exacerbate symptoms in another. Palliative care is not only appropriate for cancer: other long-term conditions have also taken up the palliative care approach. End stage lung diseases, heart failure, neurodegenerative conditions, and the multi-morbidity associated with frailty of old age, all benefit from this holistic approach to assessment and treatment that values the satisfaction of patient goals over length of life alone. Enabling people to live well enough to fulfil their potential, and to die with as little discomfort as possible, is the aim.

Early introduction of palliative care has been shown to improve quality of life [3,4], and even to extend life expectancy in some studies [5]. Accessing palliative care early can be problematic in insurance-based health economies where ‘palliative’ is often mis-translated as ‘end of life,’ so forbidding concurrent disease-modifying treatments alongside palliative care interventions. By reducing symptoms and enhancing coping of people living with long-term conditions or cancer, good palliative care from early in an illness can reduce reliance on hospital, and decrease associated health-related expenditure [6]. Where palliative care services are integrated into, for example, cancer treatment centres or long-term conditions teams, the palliative approach ensures that symptom management is measured alongside tumour markers or other outcome measures; holistic care results.

But what of the public understanding of dying?

A recent UK survey demonstrated that whilst 40% of 30,000 respondents had made a Will or written their wishes about disposal of their belongings after their death, only around 4-6% had nominated a person to represent their health and welfare wishes should they become too unwell to speak for themselves [7]. In other words, although almost half of Britons have thought about what might happen after they die, almost everybody shies away from thinking about and planning for the inevitable last part of living. Dying. People don't even like the word: euphemisms are creeping into the language of the media (the BBC often uses 'passed away' instead of 'died' when announcing deaths) and into everyday conversations.

This confirms the daily experience of those of us who work in palliative care. Although palliative care is not always 'end of life care,' patients receiving palliative care are often approaching the last months or weeks of life. As a result, palliative care staff have a lot of experience of what people do (or do not) know about dying, and how helpful it can be to check out their expectations and help them to understand what to expect.

British people's expectations about dying are interesting. In the absence of direct exposure, individuals absorb information from newspaper stories, soap opera plots and cinema. Whilst death is used as an entertainment in horror films, zombie stories and drama, normal dying is hardly ever depicted. Not realising that they are exposed to inaccurate and dramatized portrayals of dying, many patients and families dread unlikely scenarios like choking, unbearable pain, or other catastrophes. Their fears are both for themselves and for their beloved family and friends who might witness and be traumatised by their terrible death.

Because supply of adequate analgesia is readily available via the NHS, uncontrolled pain is not common in the UK. Of course, the experience of suffering is not only about the presence of absence of physical pain; suffering may arise because of emotional, spiritual or existential distress, and such distress may drive or magnify any physical symptoms, too. This is a situation Dame Cicely Saunders termed 'total pain' and addressing people's fears about the likely manner of their dying is one of the keys to managing such distress. In palliative care, we regularly meet patients whose fears about the manner of their dying are both catastrophic and ill-founded.

And so back to the beginning of this piece. After joining the new specialty of Palliative Medicine in the year of its inception, and working to serve patients, promote services, expand its research base and develop new approaches to management of physical symptoms and emotional distress, the author was faced with the dismaying realisation that public misunderstanding of dying confounds people's expectations and undermines their wellbeing once a serious or potentially fatal condition declares itself. This is not a problem to be addressed one family at a time, this is a Public Health issue. Something must be done to address the public's (mis)understanding of dying.

But who might tackle this huge issue? Who would have the experience of human lives as they reach their end in hospitals, in hospices, in care homes, in people's own homes? Who would have the knowledge about symptom management, emotional support, spiritual reckoning and the dynamics of the often-complex assembly of family, friends and supports around people living at the end of their lives? And how would one gain the public's attention and trust? Nobody wants to talk about dying. Nobody would want to read advice or take instructions about how to prepare for life's end.

As a physician who had used patient stories to educate medical students, palliative care trainees and other professions, a potential strategy became clear. Rather than giving advice, why not replicate the way people came to understand dying half a century ago, when watching and participating in the lives of dying people gave their family and friends a sense of the progression of terminal illnesses

and the stages of the process of dying? In other words, why not use patient stories as a vehicle to show, rather than tell, how dying happens?

This is how the book ‘With The End In Mind: dying, death and wisdom in an age of denial’ [8] was born. Using stories about real people encountered over 40 years in medicine, all carefully anonymised, it was possible to create a book that allowed readers to glimpse the process of dying, and the lessons learned by the narrator across her journey from medical student to senior physician. Dying forms the backdrop of the stories, so that the patterns become familiar and recognisable, yet the stories are about life and living. The narrative includes very old patients and the very young; deaths from a variety of illnesses; how families’ responses can change the patient’s experience and vice versa; and how the dying, like anybody else, are mainly getting on with the business of living.

The response to the book has been astonishing. It has sold tens of thousands of copies around the world, been shortlisted for the Wellcome Book Prize, been translated into other languages. It has been adopted by schools of nursing, medical schools and university courses for emergency medical responders. And it has generated book reviews and personal messages from readers that demonstrate how knowing more about dying does, indeed, reduce the fear and enhance the sense of peace amongst non-medical readers.

There are themes to the feedback from the book, not yet formally evaluated but clear from the large volume of messages. These themes bear careful consideration by all who care for people at the end of their lives.

Firstly, messages from the bereaved confirm that they consistently, horribly misinterpret the sights and sounds of the deathbed. As the patient’s loved ones watch them slip more deeply into unconsciousness, so that their respiration becomes simply cycles of brain-stem driven, deep-to-shallow breaths, often in a Cheyne-Stokes pattern, they mistake this unconscious reflex breathing for breathless gasping. As the dying person’s consciousness of pharyngeal sensation is lost, allowing pooling of fluids in the throat that results in the ‘death rattle’ of air bubbling through the fluid film during respiration, families are traumatised by the unfamiliar, disconcerting sound that they interpret as ‘drowning’ or ‘choking.’ Because the larynx may not be fully relaxed, resulting in involuntary vocal cord noise during exhalation, families believe that their beloved is groaning or trying to speak to them. As a result of these misinterpretations, they are convinced that their loved one ‘died in agony,’ with any professionals in attendance accused of being unaware or uncaring about that awful death.

Secondly, messages from readers who are terminally ill suggest that knowing more about the process of dying, and having more detailed knowledge of what to expect, is very comforting. Not only does the knowledge that death usually arises after a period of increasing weariness, a need for more sleep and frequent, lengthening naps, before complete unconsciousness arises, offer the comfort that most people are unaware at the moment they die; the fact that dying has a recognisable pattern and is unlikely to happen suddenly and unexpectedly gives people confidence to get on with living while they are awake. The same reaction is familiar to palliative care practitioners who describe ‘ordinary dying’ to their patients: relief, calm, hope.

Other messages from terminally ill readers mirror clinical experience of describing dying to patients. The comfort of their new knowledge is something they wish to offer their loved ones. In clinical practice, describing dying is almost always followed by a patient asking for that same information to be relayed to their family members. Messages from readers show that, having read the book, they are keen to share their new knowledge with their closest people by giving them the book or reading specific stories with them.

Thirdly, feedback from professionals who work directly with patients, or who support bereaved people, shows that the widespread lack of understanding of the physiological process of normal

dying includes those who work in healthcare, bereavement care or who offer funeral services. Most medical schools and schools of nursing now teach about pain management and symptom control in their ‘care of the dying’ curriculum, but students are not required to have bedside experience of end of life care, nor to observe the process of dying. They are thus ill-prepared for working with dying people when they qualify; in hospital practice, they are rapidly inducted to the ‘prevent death at all costs’ culture that sees death as a failure.

In the UK, as in Europe, North America, and other economies where death at home is no longer the norm and where medicalisation of dying has displaced family care at the end of life, there is a growing ‘death positivity’ movement. This is a grassroots reclaiming of death as a social rather than a medical construct, that takes the form of informal discussion groups (like Death Café) [9], training of lay carers as Death Doulas (like End Of Life Doula UK) [10], and a variety of death-advice books (see Further Reading below); some initiatives are about dying itself, others about funerals, commemoration, legacy etc., some about living with grief and bereavement. All seek to inspire people to see death as a natural end to living and dying as the final phase of life, to be lived as well as possible.

These largely lay-inspired enterprises sit alongside strategic medical programmes that seek to contain the spiralling healthcare costs of escalating futile medical interventions in the last part of life. The process of Advance Care Planning seeks to enable people to plan ahead for the last part of their lives; to express their wishes about where and how they would like to be cared for; to decline in advance any interventions they deem too intrusive, unwanted or unnecessary; and to participate in advance planning for anticipatable medical crises according to their known medical condition(s). It has been shown in a variety of studies that engaging in Advance Care Planning makes it less likely that people will have unwarranted emergency hospital admissions as death approaches. Of course, people are unable to plan well unless they have an understanding of what the likely progression of their illness, and their dying, will be like.

What are the implications for India of these observations?

To live well until the very end of life, people require excellent symptom control. Regardless of the availability of basic or enhanced healthcare, access to adequate pain relief is a fundamental human right [11]. Thanks to the campaigning of Prof M. R. Rajagopal and his Pallium India [12] movement, Indian narcotics law has been simplified enabling wider access to pain relief for millions of citizens [13], although much work remains to be done before this access is universal across all states. Likewise, there is a strategy for palliative care and access to palliative care training for Indian professionals and volunteers [14]. These are most welcome developments.

For Indian families who lack access to expensive hospital care, the progression of terminal illness and the process of dying is likely to be familiar. Sadly, it may often be experience of distress while dying if access to good symptom relief has not been available to the dying person. Whether or not symptoms were well managed, without access to good information it is likely that Indian citizens misinterpret the changes in respiration and in respiratory noises close to death just as UK citizens do.

For Indian citizens with the means to access high-level hospital care, a different difficulty is likely to emerge: the interpretation of death as a ‘medical failure’; the associated escalation of intensive treatments that will not save the life but may temporarily delay the death; a lack of recognition that death is approaching, and loss of opportunities for farewell conversations. Even when a well-palliated death takes place in optimal surroundings, those attending the death-bed may misunderstand the sights and sounds.

Public information is key to better understanding: information given in advance, and then good information as dying takes its course, so that everybody understands what they are seeing and hearing, minimising the chance of misinterpretation and consequent unwarranted distress. This requires the presence of somebody who has the knowledge, wisdom and experience to ‘narrate’ the deathbed. Sometimes this will be a nurse or a doctor; sometimes it will be a lay person recognised for their wisdom. Such wise people are often well-known in their families and communities, whether that is a rural village, a city block, a hospital or a charity shelter. Ensuring that these wisdom figures are educated to explain dying as it proceeds, and to check onlookers’ understanding to identify and gently correct misinterpretations, could substantially change public understanding, preserving the knowledge already present in Indian families and communities while supplementing it with additional explanations.

In summary:

Despite wonderful medical advances over the last 80 years, death has not been ‘cured.’ A realistic understanding of the physiological process of dying is a comfort to patients and their loved ones, and enables them to live the last part of life well provided they have access to good symptom control. Talking about dying will not make it happen sooner. Not talking about dying maintains the silence and fear of the unknown that robs people of their chance to make their peace at the end of life. Maintaining and building the public understanding of dying is imperative.

Further Reading:

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Dr. Kathryn Mannix FRCP is a retired consultant in palliative medicine from the North of England. She worked in hospitals, hospices and community palliative care settings in the UK for 30 years. Her research interests were in palliation of nausea, development of Cognitive Behaviour Therapy (CBT) for palliative care patients, and development of CBT training for palliative care staff. She took early retirement to campaign for better public understanding of dying.

Her first book, *With the End in Mind*, was published by William Collins in December 2017 and is available here https://www.amazon.in/End-Mind-Dying-Wisdom-Denial/dp/0008245592/ref=sr_1_1?keywords=kathryn+m Mannix&qid=1579690672&s=books&sr=1-1