

Re-imagining long term-care

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Lesson one: Ageing is not a sickness

Case study/lesson

Until the mid-1900s, it was assumed that most Americans in the US would spend their declining years in the care of their families. But after two world wars, a global depression and an epidemic of Spanish flu that would kill and displace between 3% and 5% of the earth's population, the fabric of family life began to fray. Old people were turning up in droves in poor houses as the only viable option for long-term care.

Policymakers in the US saw a pension system as an antidote to the problem, but even after the *Social Security Act* was introduced in 1935, the numbers of elderly who turned to poorhouses for refuge refused to drop.

Obtaining enough money to pay for a home wasn't the issue: "Pensions hadn't provided a plan for that final, infirm stage of mortal life¹."

From dying at home to nursing homes

At the same time, advances in medical science were fundamentally changing the way we viewed ageing. As age-related health problems invariably arose, we turned more and more to the medical profession for answers. As a medical problem, this meant ageing was potentially 'fixable'. Philosophically, we would shift from thinking of death and dying as the inevitable, to 'find out what's broken and then fix it for me'.

In 1945 in the US, most deaths occurred at home. By 1980, though, only 17% occurred at home², as ageing was migrating to medical centres. The more the aged in frail conditions stayed on, the more untenable the pressure became on the hospital system. Out of these capacity constraints, the concept of the nursing home emerged.

Ageing had moved from being a natural, family-centred problem to a medical problem, then to an institutional problem. But the institutionalisation of ageing would have (and continues to have) its own perverse outcomes. Entering into such institutions as nursing homes and old age homes effectively meant relinquishing autonomy over one's life. In the interests of keeping people safe and keeping costs as low as possible, people in long-term care institutions found their lives regulated on every possible level. Controlling quality of care was not the same as creating quality of life.

The net effect: "We achieved some important societal goals of freeing up hospital beds, taking burdens off families, coping with poverty, but never the goal that matters most to the people who reside in them – how to make life worth living³." As Gawande describes it, we had lost the ability to be the authors of how our story would end – and this was an important exercise in giving meaning to our lives.

Beyond nursing and old age homes

In response, a continuum of care evolved over the next 50 years. From retirement villages that could mirror home life to assisted living, frail care, and finally to hospices, each facility would try to strike the right balance between the need for medical care and individuals' autonomy.

Ironically, the biggest impediment would turn out to be the insurance industry. It insisted on keeping a firm grip on how much free will people could have in these facilities. It incentivised the medical support system to do just about anything to keep elderly people alive, but did little to help them come to terms with the inevitability of ageing. As Gawande points out: "We pay doctors to give chemotherapy and to do surgery but not to sort out when this is unwise ... The issue isn't merely a matter of financing. It arises from a still unresolved argument about what the function of medicine really is – what, in other words, we should and should not be paying doctors to do⁴."

This changed in an interesting but important way as a new concept of care moved to centre stage: palliative care. Palliative care first emerged in Canada in 1979 and was specifically developed to serve patients with life-threatening illnesses. Thought of another way, palliative care actually cares for those who are dying – for whatever reason. What made it unique was that it focused not on healing, but on relieving pain and

identifying the best ways for an individual to feel as comfortable and 'normal' as possible in their remaining months. Its approach is holistic: the best palliative care programmes go beyond the purely physical to address social, legal, economic, psychological, spiritual and human rights considerations. Essentially, palliative care is about quality of life – or what's left of one's life⁵.

Perhaps the most important lessons from palliative care were the insights it provided the medical profession into the destructive power of treating ageing too much as a medical problem. A 2016 study in the *International Journal for Quality Healthcare* highlighted the fact that, on average, 33% to 38% of patients who had entered the end-of-life period received invasive treatments that were of no medical benefit to them. Between 33% and 50% of patients who had expressly requested do-not-resuscitate were similarly subjected to these non-beneficial treatments. On some level, this highlights just how difficult the decision is about when to treat and when not to treat. Near death, hope springs eternal⁶.

When patients were provided with palliative care options, the impact was significant. In a number of randomised studies in the US and UK, patients who received palliative care were found to have lower depression, less pain, and actually lived longer than those who underwent traditional interventions of chemotherapy or surgery⁷. If medical interventions meant individuals ended their lives separated from their loved ones in sterile hospital wards and enduring the indignity of painful medical procedures, eating tubes and breathing machines, surely palliative care provided a better quality of life at the end. As a further bonus, palliative care also appears to reduce post-death trauma for family members.

Palliative care can relieve the financial pressure of using expensive medical interventions and hospital beds while at the same time restoring autonomy and dignity to people's lives.

In South Africa, the palliative care movement is gaining significant traction. In many ways, it is ideally suited to the South African social environment. The power of palliative care is that it can be integrated into community-based home care. The most visible presence of palliative care in this regard has been in relation to the treatment of HIV/AIDS in rural areas. In fact, there have already been a number of successful programmes, specifically in KwaZulu-Natal, demonstrating a model of care that integrates hospice, home-care, and palliative services specifically to address the needs of HIV/AIDS patients⁸.

The next big challenge for palliative care will likely be dementia. Already, dementia is set to be the next big killer globally. In the UK, researchers from King's College have projected that dementia will overtake cancer as the number-one killer by 2040. There is an all-out call to double the current capacity for palliative care capabilities to meet this eventuality. In South Africa, dementia, and not necessarily ageing, may provide the critical wake-up call to policymakers about the tsunami of long-term care capacity that will be required here. Dementia is most decidedly not an aspect of ageing that families can manage on their own. But we will get to the issue of how unprepared South Africa is in this regard in the next section.

Lesson two: Ageing is a young science

Case study/lesson

One outcome of placing so much medical attention on ageing is that we are beginning to understand how different the medical needs of the elderly are. However, ensuring medical and nursing professionals are properly trained in those distinctions has not been seen as a priority. But the consequences of not knowing are severe. Consider these examples:

- > An older body can respond to medication and treatments very differently, and with serious consequences.
- > Elderly people often suffer from multiple medical conditions that are treated by multiple medical specialists whose various treatments may not be coordinated by any central function.

Overmedication or incompatible medical treatments are common and can leave patients in a more debilitated state than normal ageing would suggest.

- > Medical professionals will frequently make assumptions about the ageing process: our memory becomes poor, our senses and nerves become impaired, we develop incontinence or lose control over other bodily functions. When they are confronted with these ailments in an older person, they choose to leave the problem untreated. Frequently, these problems are treatable. The question is often: Should we bother?
- > Medical professionals work on a process of triage: identify the worst problems and treat them first. But care for the elderly needs a different process because so many problematic things are happening to the body at the same time. It's not so much a process of 'fixing' as 'fine-tuning' so that the elderly can live as expansive a life as possible. That means the gerontologist must know every detail about how a person is living their lives and identify ways the process can be fixed. How do we make sure that person can still move without falling, get the right nutrition, ingest and digest what they need? How can we make sure there's adequate attention to daily hygiene? For the elderly, these small things about one's day-to-day care can have great significance.

Table 3: Conventional care versus older-person-centred and integrated care

Conventional care	Older-person-centred and integrated care
Focuses on a health condition (or conditions)	Focuses on people and their goals
Goal is disease management or cure	Goal is maximising intrinsic capacity
Older person is regarded as a passive recipient of care	Older person is an active participant in care planning and self-management
Care is fragmented across conditions, health workers, settings and life course	Care is integrated across conditions, health workers, settings and life course.
Links with health care and long-term care are limited or non-existent	Links with healthcare and long-term care exist and are strong
Ageing is considered to be a pathological state	Ageing is considered to be normal and valued part of the life course.

Source: World Health Organization. 2011. WHO Study on global AGEing and adult health (SAGE).

Medical care for the aged is a separate area of specialisation that focuses less on fixing problems and more on knowing how to anticipate and better manage them. This is not about saving lives any more – it's about helping people manage the winding down of the clock. Studies of patients who use these specialists suggest that these patients are 25% less likely to become disabled, 50% less likely to suffer from depression and 40% less likely to require home health services⁹. Yet although these specialists add significant value to life, this area of medical specialisation is on the decline. Not only is the funding not there (our far higher priority is youth, which is probably understandable) but there's no glory in it. There were only six gerontologists in South Africa at the time of writing.

Lesson three: Asking the right questions makes the critical difference

Case study/lesson

When medicine took over the ageing process, medical professionals made the triage decisions. Depending on the medical technology available and the associated costs, medical professionals would determine what your body would be subjected to. The answer? As much as possible, if medical insurance was available.

The most important insight to come out of palliative care and gerontology is that much of this life-end physical abuse, trauma and cost could be avoided by following one simple process: ask the patient. It's a principle that seems to run counter to the medical assumption that your doctor knows best. Yet when medical professionals took the time to have that difficult conversation with their patients about what constituted a life worth living, and under what conditions, the results were astonishing.

They asked questions such as: Do you want to be resuscitated if your heart stops? Do you want aggressive treatments such as intubation or mechanical ventilation? If a surgical process left you incapable of movement, would you still proceed?

In hospitals that undertook these discussions, medical costs dropped to half the national average, patients spent half as many days in hospital and, the greatest surprise of all, life expectancy actually increased by as much as a year¹⁰.

Each one of these lessons points to a process that ultimately reduces rather than increases healthcare costs, and increases quality of life at the end by reaffirming family and community support systems.

Can South Africa not benefit here? The next session addresses the particular challenges for our country.

References

1 Gawande (2015), p. 70.

2 Gawande (2015), p. 72.

3 Ibid. p.77.

4 Ibid. p. 187

5 World Health Organization

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7 The Economist. 29 April 2017. *End-of-life care: A better way to care for the dying*.

8 Defilippi, K. 2005. Integrated community-based home care: Striving towards balancing quality with coverage in South Africa. *Indian Journal of Palliative Care*, 11(1), 34.

9 Gawande (2015), p. 46.

10 Gawande (2015), p. 179.

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