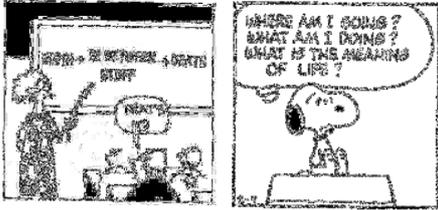


Changing Demographics & Changing Metaphors:

The musings of a middle-aged ethicist on death and dying in New Zealand



John Kleinsman PhD
 Director – The Nathaniel Centre
 Chairperson – The Care Alliance

Nathaniel Knoef

Nathaniel Knoef was born on 12 December 1998, as the pohutukawa flowers were beginning to appear. He died on 2 February 1999 as the same flowers faded, giving way to the seed from which new pohutukawa grow. At his birth, Nathaniel was diagnosed with incurable health problems, and his parents faced many ethical issues associated with his care. The naming of New Zealand's national Catholic bioethics centre in honour of Nathaniel is a sign of the Centre's **commitment to those who are the most vulnerable** in the **complex ethical situations** which develop in their lives.



Nathaniel Knoef



Dancing with Mister D

*Doctor, why am I ill?
 Your heart valve leaks.
 Yes, but why me?
 Wait, I'll call the vicar.*



Teilhard de Chardin



We are not human beings having a spiritual experience; we are spiritual beings having a human experience.

(Pierre Teilhard de Chardin)

Evil and suffering ...



“By and large, the religious thought of humanity tries to **explain the existence of evil**: it is for our testing; for our improvement; for punishment; it is inevitable; it is an illusion and so on. But **Christianity refuses all these explanations ...** [defining] evil as a **privatio boni**: a privation of the good, a parasite on being: a distortion, not a thing in itself ... **evil has no justification at all**, because it has no part in the good, in God, in God's future; it was not designed, not purposed, not planned into reality ...

Evil and suffering ...



... We are to say to the victim: **this is an outrage, an affront and God will not have it** ... God's good news is such a total non-compromise with evil that it **offers no justifying or pacifying claims to take away our rage and claim**, to make things 'OK'. Things are not OK. And God does not ask us to pretend that they are.

To say this is not to deny for a moment the mystery of redemptive suffering ..."

Carmody Grey – *The Tablet*, 14 November 2015.

John Dickson

"Ancient Greece and Rome, the cultures against which Christianity first competed, had little by way of philosophical reasoning that could guarantee the **inherent worth** of those lacking rational capacity or social utility ..."



John Dickson

... So infanticide was common and social welfare for the aged and dying was virtually non-existent. Christianity changed all of that. It inherited from Judaism a theology of human dignity and a program of social welfare [grounded in the belief] that Christ had died for all, even for the lowly and neglected."



Victor Frankl

"But **today's society is characterized by achievement orientation**, and consequently it adores people who are **successful** and **happy** and, in particular, it adores the **young**. **It virtually ignores the value of all those who are otherwise, and in so doing blurs the decisive difference between being valuable in the sense of dignity and being valuable in the sense of usefulness.** If one is not cognizant of this difference and holds that an individual's value stems only from his present usefulness, then, believe me, **one owes it only to personal inconsistency not to plead for euthanasia** along the lines of Hitler's program ..."

Victor Frankl

... that is to say, **'mercy' killing of all those who have lost their social usefulness**, be it because of old age, incurable illness, mental deterioration, or whatever handicap they may suffer. **Confounding the dignity of man with mere usefulness arises from conceptual confusion ...**

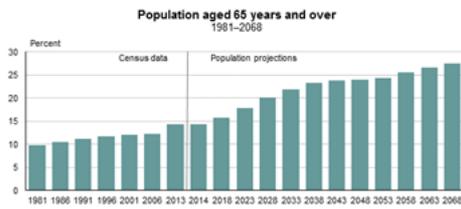
Viktor E. Frankl, *Man's Search for Meaning*



The Current Context

- People are living longer ...
- **Baby boomers are reaching retirement** ...
- Families are smaller ... and more widespread ...
- Pressure on health resources ...
- **Increasing social isolation of the elderly** ...
- **Commodification of the elderly** ...
- Socio-economic constraints ...
- Fear of death and alienation from dying ...

Demographics



Source: Statistics New Zealand

- 65+ age group has nearly doubled since 1981
- The proportion of people under 15 years: 26.9% in 1981 to 15.9% in 2063
- The proportion of 85+ projected to nearly double by 2063 to 23.4%

Source – Statistics NZ

The 'burden' of the aged

“A major motivating factor for me attending your presentation was a panel discussion on National Radio some weeks ago which I found alarming. Jim Mora asked his panellists' for their opinion on euthanasia and assisted suicide. His first panellist used expressions like **'the growing aging population'** and the **'population bulge at that end'** before speaking of her father who had had dementia for two years and no longer recognised her. She went on to say ... **'he's no longer my dad, they're just keeping him alive and the taxpayer is funding this.'**

The 'burden' of the aged

... I found it almost chilling that expressions like **'increasing aged population'** and **'taxpayer burden'** could be used in the context of a rationale for euthanasia. I expected an outbreak of twitter and email protests to the radio programme but there was no apparent reaction other than expressions of empathy for her father's situation. All of this seemed to accord with what you said about our society's increasingly functional view of the value of human life.”

Speed Hump Ahead



Role of Metaphors

- Metaphors shape the ways we think about problems and the types of solutions we investigate
- Metaphors play an important role in the realms of imagination & feeling
- Different metaphors support different strategies
- The choice of metaphor has ethical significance – it is often settled

Susan Sherwin, 2001,
Feminist Ethics & the Metaphor of Aids

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Language & Metaphors

“Metaphor is shown to reflect and generate narratives related to what health is. What affects health and what can be done to improve health ... **Metaphor and narrative are powerful constructs with positive and negative actual and potential outcomes.**”

J Talley, Metaphor and Narrative and the Promotion of Public Health Genre 44, 3 (2011).



Language and Metaphors



Simulation shows the high cost of dementia, especially for families

August 17, 2017 News contact: [David Cochrane](#), 405-883-1882

Missing Miss
A new study that projects the costs of dementia care with their family members, rather than public insurance programs.

A new simulation of the dementia epidemic estimates the economic impact the disease has on households and public insurance programs and provides a tool for projecting the impact that different interventions could have.

PROVIDENCE, R.I. (Brown University) — A new simulation of how the costs and the course of the dementia epidemic affect U.S. families finds that neurodegenerative conditions can more than double the health care expenditures of aging and that the vast majority of that financial burden remains with families rather than government insurance programs.

The total average cost to care for a person with dementia was more than \$21,000 over about five years, compared to an

Language & Metaphors

RETIREMENT

Caring for aging parents costs Canadians \$53 billion a year — and it's just going to get worse

By [Lillian Weiler](#) and [Liz](#)



"Lower income Canadians bear the **largest dollar burden** when it comes to their aging parents ... The CIBC report states **the problem may be worse** than their report findings because studies out of the United States suggest when it comes to assessing care for elderly parents and expenses, people usually underestimate what they spend"

Language & Metaphors

PublicQeek

The burden of aging: a theoretical framework for understanding the shifting balance of caregiving and care receiving as cohorts age.

Abstract
Unless changes occur in the way cohorts age, the future aging of the population will make the burden of caring for older persons an increasingly salient political issue in American society. There is no reason, however, why aging in the future should replicate the pattern of aging that currently exists. A helpful step toward understanding what social changes would reduce the burden that aging cohorts place on society is the development of aging theory. This article develops a theoretical framework that explores factors determining the level of care given and care received by cohorts moving through different stages of later life. Four proximate determinants of caregiving and three proximate determinants of care receiving are specified. Once the proximate determinants are identified, attention is focused on social changes that could reduce the burden of aging produced by cohorts aging through later life in the future.

"A helpful step toward understanding what social changes would reduce the burden that aging cohorts place on society ..."

Language & Metaphors

Healthcare system unprepared for 'tsunami' of elderly patients



We are totally unprepared for the impending "tsunami" of our aging population (Stock photo)

Shane O'Brien
June 2, 2015, 2:30 AM

We are totally unprepared for the impending "tsunami" of our aging population which could "collapse the entire acute hospital network", according to some of the country's leading authorities on geriatric care.

How do you stop a metaphor?

A POPULAR METAPHOR

HOW DO YOU STOP A METAPHOR?

at the Pacific we have experience with tsunamis: great walls of water that destroy or displace everything in their path and then recede, leaving nothing behind but rubble, salty mud, and broken lives. There's nothing human about a tsunami. It's a nasty metaphor for older adults. Andrea Charney (2012) points out that "it testifies to the barely conscious figurative language that serves to construct perceptions of an aging population"—inaccurate, damaging, perceptions, at that.

The "unthinkable" becoming not just thinkable but acceptable

Written Submission to Health Select Committee: No. 1

"My Husband and I are **an older couple in our 70's** and both strongly believe in Euthanasia ... **The cost of both Nursing Homes and Palliative care is enormous** and we believe that **the money spent on this could be used for medical research or for patients that can get long term benefit ...**"

https://www.parliament.nz/resource/en-NZ/51SCHE_ENVI_51DBH0H_PET63268_1_A476175/92341eda565084b85471fb008f5a2c5ab439e71a



The “unthinkable” becoming not just thinkable but acceptable

Written Submission to Health Select Committee: No. 2

https://www.parliament.nz/resource/en-NZ/515SCHE_EVI_510BHOH_PET63268_1_A473927/f5d316e03d6fb9bf67f29d6a2e23741957913d

“Many people who would opt for MAD depend heavily on the Health Services. When they would make use of MAD **the Health Services would save much money**. They can use that for people urgently needing the Health Services. Waiting lists could be reduced and subsequently the suffering of patients.

A properly designed MAD law would leave very little room for misuse.”



The “unthinkable” becoming not just thinkable but acceptable

Written Submission to Health Select Committee: No. 3

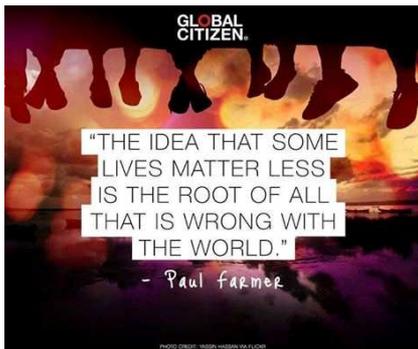
https://www.parliament.nz/resource/en-NZ/515SCHE_EVI_510BHOH_PET63268_1_A469366/a2378b25a85aac5373abc08f2178f2358f7dc492

“Many people are kept alive to endure drawn out deaths and unnecessary pain. **This drive to keep people alive at all costs soaks up a huge amount of resources – human as well as financial - which could be better invested in vulnerable children at the beginning of their lives.**

I feel there is to [sic] much sanctity around the idea of a human life and not enough sanctity around the quality of that life - whether that be in dying or living.”



Paul Farmer



Changing the Social Narrative

- In the face of the shift to a more functionalist narrative, we must renew our commitment to the most scrupulous respect for all human life, irrespective of its quality.



Palliative Care: the Pearl of Great Price

“One reason global palliative care advocacy is so challenging is because it implies systems change. Palliative care is an *approach, an ethic*, a multi-disciplinary sub-speciality, not just a new element that can be added and stirred into health systems.

Palliative care doesn't accommodate itself to the existing global health ideology, but challenges the ground of that ideology, which is fixated on fixing, on making populations fit to contribute to “development.” **From the development perspective, the distinct ethics of palliative care are perverse, claiming the inherent value of each person and family, from fragile neonate to frail elderly, those who don't contribute to the bottom line.**

Palliative Care: the Pearl of Great Price

“More subversively still, palliative care advocates request that governments *subsidize* palliative care as part of the public health system, **as a human right**, rather than relegating the service to the mercy of charities and private philanthropic organisations ... Palliative care advocates are **irritants to systems largely focused on treatment**, systems whose organising principle decrees that patients be abandoned when cure is no longer an option. Palliative care invites us to **explore areas of life beyond strict utility**, as defined by ordinary standards in society, and the ultimate limits of life. **Such exploration is only possible if we recognise there can be great value in what is not useful ...**

Palliative Care: the Pearl of Great Price

"The fact that we are *all* vulnerable, *all* subject to suffering, old age, and death, makes strategies of **avoidance through domination and control** both futile and painful for all parties, particularly those outcast by serious illness ... Indeed, **palliative care is a discipline that demands its practitioners become conscious of themselves in order that they may be properly vulnerable to the vulnerability of the other.** By definition, becoming conscious of oneself requires the courage to be with, to **live into the truth of suffering**, no matter how unpalatable or *dis-grace-ful*. Only then can pathology be transformed, alchemized, healed by grace, etymologically related to gratitude for Being itself ... **Approached with courage, friendship, and honesty, the shared pain is transformed and eventually healed.**