Compassion in Palliative Care and the impact of technology on the diagnosis of dying

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Critical questions

- What do we mean by compassion?
- Why is it important
- Technological advancement – friend or foe?
- How do we cultivate a truly compassionate response from those who practice palliative care?
And a set of sub-questions

- What do we mean by the concept of futility?
- When is enough, enough?
- The Mastermind question‘ I have started, so I will finish....’ ?
- Technology as issues of choice and decision-making (makers)
- Technology as an exercise in documentation and discourse?
WHAT DO WE MEAN BY COMPASSION?
A journey through suffering
Compassion as a response to suffering

- Suffering cannot be treated unless recognized
- Having the courage to ask
- Having the strength to wait
On Empathy

- Empathy reflects a heightened focused awareness of the experience of another person as something to be understood but not necessarily suffering. It is, therefore, an awareness of another person’s experience, but does not entail the intention to relieve suffering nor the skills required to do so.

The action of compassionate care as the reconstruction of broken lives
Global compassion
“You matter because you are you and you matter to the last day of your life. We will do everything we can to help you die peacefully and to live until you die”.

Psychosocial

Spiritual

Physical
A spiritual dimension of compassionate dying
Compassion asks us to go where it hurts, to enter into places of pain, to share in brokenness, fear confusion and anguish... Compassion means full immersion in the condition of being human.

Archetypes of compassion
1st principles

- Compassion
- Commitment
- Confidence
- Communication
- Collaboration

‘The real presence of another person is a place of security’
(Saunders C, 1976)
WHY IS COMPASSION IMPORTANT?
What have learnt about compassion in our society?
Challenges in care delivery

- Compassion assumed to be central to palliative and end-of-life care
- Concern in UK over compassion ‘lost’ in healthcare
  - [http://midstaffspublicinquiry.com](http://midstaffspublicinquiry.com)
- Concern by palliative care practitioners that increasing technology in healthcare challenges best practice. How true is this?
And when compassion fails...
Can we learn compassion?
The Evidence

Impact of a contemplative end-of-life training program: Being with dying

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Impact of a contemplative end-of-life training program: Being with dying

ABSTRACT

Objective: Healthcare professionals report a lack of skills in the psychosocial and spiritual aspects of caring for dying people and high levels of moral distress, grief, and burnout. To address these concerns, the “Being with Dying: Professional Training Program as Contemplative End of Life Care” (BDPC) was created. The purpose of BDPC is based on the development of mindfulness and resonant attention through contemplative practice, so that cultivating empathy and emotion-based compassion is motivated to enable clinicians to respond to patients and families with compassion. This study describes the impact of BDPC on the participants.

Methods: Ninety-five BDPC participants completed an anonymous online survey. All completed a confidential open-ended telephone interview.

Results: Four main themes were identified: the power of presence, cultivating balanced compassion, recognizing grief, and the importance of self-care—enacted in the interviews and supported in the survey data. The interviews included BDPC's contemplative and reflective practice meaningful, useful, and valuable and reported that BDPC provided skills, attitudes, behaviors, and tools to change how they worked with the dying and bereaved.

Significance of results: The quality of presence has the potential to transform the care of dying people and the caregivers themselves. Utilizing this quality within themselves and others allows clinicians to explore alternative to exclusively clinical, procedural, and task-oriented approaches when caring for dying people. BDPC provides a comprehensive curriculum that equips clinicians with the knowledge and skills to provide compassionate care for dying patients, families, and caregivers.

KEYWORDS: End of life, Professional education, Compassion, Resonance, Mindfulness

INTRODUCTION

The hallmark of palliative end-of-life care is holistic, relationship-centered, and compassionate care of patients dying with life-limiting conditions and their families. A number of curricula (Kocher & Ferrall, 2000, Ferrell et al., 2002; Rock et al., 2002; Liu et al., 2004; Hescott & Reslow, 2005; Ferrall et al., 2005; Watanabe et al., 2006; Ogg et al., 2008; Sullivan et al., 2009; Peters et al., 2010; Koff et al., 2009) using different teaching methods (Williams et al., 2001; Hescott & Reslow, 2005; Frans-Edwards et al., 2006; Forell et al., 2007; Weissman et al., 2007; Moore et al., 2008) have been developed to give healthcare professionals the knowledge and skills to care for dying people.
Can we learn to be more compassionate?

- A resounding Yes....and a resounding No
- What does it mean to be a good clinician?
- An inner resource that sustains and nourishes us
- A beacon which governs clinical decision-making
- A language to express the essence of changing goals of care
Compassionate responses

- Not taught, but modelled
- Teaching of the ‘why’, not the ‘how’.
- Developing ‘Palliative’ comportment
- Teaching self-compassion
Technology – friend or foe

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Your Life, Your Death: Exploring the Boundaries between Life and Death

Modern dying: from securing rights to meeting needs

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Modern medicine has transformed the dying experience. In the developed world, most of us no longer die from infectious diseases or sudden accidents, but from chronic, disabling, but progressive illnesses. Yet the U.S. healthcare system is not designed to meet the needs of people with chronic illnesses or of frail elders. In addition, our system incentivizes the use of technologies that are often helpful when an underlying condition is reversible but, when used very near the end of life, may actually prolong the dying process and increase burden on the patient. This state of affairs renders many people near the end of life without adequate symptom control, little or no social and psychological support, and inadequate involvement in decisions about when and how best to use modern technologies. This paper traces efforts over the last three decades to address problems related to modern dying. The author sees three phases: an early phase focused on securing patients’ rights to refuse unwanted treatments, the next phase focused on building the specialty of palliative medicine, and the third and future phase must redesign our healthcare system to better align with how we live in the 21st century.

Keywords: dying; palliative medicine; patients’ rights; unwanted treatments

Introduction

In the span of a few decades, human beings in the developed world have gone from dying from infectious diseases or sudden accidents to dying in a wholly new and very indeterminate way. Most of us now live longer with chronic illnesses that slowly progress to death. Modern medicine has transformed the human experience from one of rapid death over which we had very little control to a slower process that we often live with for years. Obviously, there are many benefits, and most of us are grateful that we live in this age of modern medical technology. However, it is a familiar deal with real quandaries. We do not have adequate systems of care for people with advanced illness who are often isolated and alone, or dependent on family members who themselves become ill or impoverished from their caregiving duties, no matter how unselfishly rendered. The vast proportion of the population who are now aging require a different kind of health system, one better able to provide not only acute medical services, but also the psychosocial and logistical supports that can adequately support frail elders. Unfortunately, we are a long way from being able to meet those needs. The current system incentivizes the use of high-technology solutions and is failing to meet the needs of the aging.

Equally problematic, we are often the victims of our own technologies, which have been called “hollow technologies,” because in many advanced illnesses, the medical interventions we offer people may prolong life, but too often they simply prolong the dying experience and cannot reverse the underlying fatal condition. Then the questions become: How much technology to accept? When do the technology’s burdens outweigh the benefits? Who should decide?

One way to tell the history of our attention to the problem of modern dying is to see it as a progressive story in at least three phases. In my telling of this story, the first phase aimed to secure the rights of dying patients by ensuring that they would not receive unwanted treatments; in the second phase, attention expanded to meeting patients’ needs for better pain and symptoms management, primarily through the
Key arguments

- A society of chronic life-limiting disease
- Technologies are incentivised by health systems
- Technologies helpful in reversible disease
- In dying, add to the burden of suffering
- Poor diagnosis of dying leads to:
  - Poor opportunity for optimal symptom management
  - Limitations to discussion around choice and preference
  - Failure to address the wider psychosocial/spiritual
‘Modern medical technology...a *Faustian* deal with real quandaries. We do not have adequate systems of care for people with advanced illness who are often isolated or alone, or dependent on family members who may themselves become ill or impoverished from their caregiving duties, no matter how unselfishly rendered’.

And so..

- Technology questions need sound preparation.
- The right to say No, does not imply a right to say Yes to other ineffective treatments.
- Healthcare professionals are not patients instruments.
- The need to avoid decontextualized questions.
- Building and redesigning a new architecture of care.

- In a technological-driven health system, do we need to ‘
re-learn how to die’ (Ryan-Harshman 2016).
HOW DO WE CULTIVATE A TRULY COMPASSIONATE RESPONSE IN OUR CURRENT HEALTH SYSTEM?
The risk

法学家说：“刚我还在想我太老了，不能再熬夜了。然后一个全然、脆弱、痛苦的人出现在我面前，我的心再次打开了。”

（Gary Pasternak, MD）
In order to have compassion for others, we need to have compassion for ourselves’
Pema Chödrön
Compassion as our guide
Who am I who cares?
Listening to the still small voice
What does it mean to Love?

‘No-one was sent into the world without being given the infinite possibilities of the heart’

John O’ Donohue
Final thoughts

‘Ar scáth a chéile a Mhairimíd’
We live in the shadow of each other
After the months in bed,
Those Sundays to Fridays, Waiting for the morphine
After the days and weeks of the kept-up face For her sisters and brother
After the last words to her daughter and son, Nurse came to lay her out.
  At the loneliest moment, she sings a fragile lullaby, each note a petal of comfort.
She was then mother of the world, rocking her baby to sleep, after the pain that was prayer
‘You are the difference you make’
Henri Nouwen
In conclusion

- ‘I wonder…’
- Be sustained in what you do
- Be nourished by the wisdom of your compassion