
Palliative Care in Oncology

Bernd Alt-Epping • Friedemann Nauck
Editors

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 Springer

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Foreword

A Palliative Care Revolution

Irene, a 59-year-old patient with cancer of the breast and bone metastases at a London cancer hospital, ruminated on care, treatment, death and bereavement.

She began with

This is a wonderful place....they have a cure for everything

and ended with

They are just going to get me through to Christmas....and then decide what to do with me.
I'm worried about Bill looking after himself.

I just listened. She took just 6 min to tell me her story.

Two months later, after her death, her husband, Bill, told me,

She was so thin, her wedding ring fell off – that hurt. She told me it hurt to hug her ... I couldn't even hug her.

The generic palliative care skills of trust building, full attention, listening, reflecting back, open questions and well-paced interspersing of information giving and inquiry were just some of the skills used to coax out what was most worrying for Irene and later her bereaved husband. The skills are almost invisible.

This is one patient's narrative. Narrative medicine encourages us to listen and tease out patients' stories to reach the pain in whatever dimension the patient and those close to them are experiencing it. O'Brien, quoting Elwyn and Gwyn (1999), reminds us, 'for all the science that underpins clinical practice, practitioners and patients make sense of the world by stories' (O'Brien 2013).

Cicely Saunders turned patient narratives and stories into a philosophy and practice of 'total care' for dying people, which revolutionised the care of people with advanced cancer and other conditions with the opening of St Christopher's Hospice, London. The story that founded modern palliative care happened over 60 years ago. The founding patient (Clark 2002, p 273), who inspired the young Cicely Saunders, then a social worker having had to abandon a career in nursing, was David Tasma, a 40-year-old Polish Jewish refugee who was dying of cancer of the rectum, which was inoperable and obstructive, for which he had a colostomy. His symptoms were pain and vomiting. He was a patient at St Thomas' Hospital, London, when Cicely,

driven to improve the experience of people who were dying, spoke with him about her vision to build a place away from a noisy acute ward where people could die in peace and dignity. Cicely Saunders had 28 conversations with David Tasma (Gunaratnam 2013).

At the relatively advanced age of 33, Cicely Saunders started to train in medicine, having been advised by a senior doctor that it was ‘the doctors who abandon the dying’. She then carried out her groundbreaking research: the recording of 1,100 patients talking about their experiences of pain; the only methodology, she told me, was *listening* to patients (Oliviere 2000). From that evolved the concept of ‘total’ pain and the concept of holistic care, i.e. ‘total care’ for body, mind and spirit delivered by a multi-professional team.

David Tasma died on 25 February 1948, having said to Cicely, ‘I want what is in your mind and in your heart’. She took that to be an invitation to mean everything of the mind ‘research, learning and full scientific rigour always matched with the friendship of the heart’ (Saunders 2000) that humanity needed for good care of the dying. He died and left her £500 in his will, declaring that he would not be in her dream of a home where people would die, but he would be ‘*a window in your home*’.

Cicely Saunders founded ‘the home around the window’, St Christopher’s in South London, in 1967, and the window at the original entrance to the hospice is dedicated to David Tasma. People come from around the world to see it. For Cicely Saunders, the window was an important symbol of openness – a call to openness to others and to the world. This openness extends to our professional practice, to our patients, to the families with whom we work, to those whom we train and to ourselves and our colleagues but also to future challenges (Saunders 2000). David Tasma was well qualified to be the founding patient of palliative care. He was experiencing multiple social and spiritual problems of learning a new language, housing and financial needs and employment and searching to make sense in his illness shortening his young life. He also represents disadvantaged patients: minority ethnic and refugee-status and minority communities needing to access good palliative care. So the opening of St Christopher’s hailed a revolution in the care of oncology patients with advanced conditions. The vast majority of palliative care until recent years was for cancer patients. From its inception, palliative care involved the trinity of care, research and education.

So what was the nature of the revolution that one woman inspired by David Tasma and many other patients led?

Barbara Monroe, the current Chief Executive, states that this revolution included

- Meticulous attention to symptom control
- Life, not just death
- Health, not just illness
- Possibilities as well as problems
- The whole individual, not just the physical body
- Families and communities
- Care beyond death into bereavement
- Multi-professional teams and volunteers

- Does not deny suffering – offers support
- Supports coping
- The belief that a little goes a long way (Monroe B, 2010, personal communication)

Forty-six years on, St Christopher's continues to innovate and to evolve modern palliative care and end-of-life care services as contexts have changed.

This book aims to integrate and push forward the knowledge base for palliative care in oncology. The book's comprehensive approach will prove useful for clinical practice including vital elements of good symptom control, good communication at all levels and good family support. Congratulations to the editors, whose expertise in palliative care is renowned and who have collected a number of prestigious contributors in this volume. They open a window for those who wish to learn and gain new vistas in palliative care.

Prof. Ventafrida (2000), one of the founders of the European Association of Palliative Care (EAPC), stated at the very first EAPC Research Congress in Berlin in 2000 that

Palliative medicine is only part of palliative care: 50 %.

The other 50 % is the holistic approach. Both make up palliative care.

Integrating good palliative care with oncology raises many challenging questions. This book holds some of the answers.

London, UK

David Oliviere

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