

END OF LIFE CARE: EVERYONE'S BUSINESS

Components of patient- centred care

Professor Liz Lobb
Calvary Health Care Sydney
University of Notre Dame

Person-centered care

- “People approaching the end of life should be seen as individuals, treated as a person not an illness, retain as much control as possible, be supported to be as independent as possible, and have their strengths, abilities and values acknowledged” [National Council for Palliative Care \(2015\) UK](#)

Definition

- Based on principles of respect, dignity, choice and independence. The **individual** receiving care should be at the centre of every conversation, action and decision.
- Their specific needs, wants and individual circumstances should guide all care and support offered by professionals. The individual is the expert in their own life and should be empowered and supported to retain control.
- **NHS Health Education England**

Question?

- The Western culture of individualism, consumerism and ethical notions of autonomy are not always accepted individually or within all cultural groups.
- How do we balance the role of families and individuals in delivering end of life care?

Broader definition - Patient-Centered Care

- *“Health care that establishes a partnership among practitioners, patients and their families (**when appropriate**) to ensure that decisions respect patients’ wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care”*
- *Institute of Medicine (IOM)*

6 Core components

- Education and shared knowledge
- Involvement of family and friends
- Collaboration and team members
- Sensitivity to non-medical and spiritual dimensions of care
- Respect for patient needs and preferences
- Free flow and accessibility of information

Core concepts

- **Dignity and respect**
 - Health Care Practitioners (HPs) listen to and honour patient and family perspectives
 - Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care
- **Information-sharing**
 - HPs share communicate and share complete and unbiased information.
 - Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making

Core concepts

- Participation

- Patients and families are encouraged and supported in participating in care and decision-making at the level they choose

- Collaboration

- Health care leaders collaborate with patients and families in policy and program development; implementation and evaluation; in health care facility design; in professional education; and in the delivery of care

Evidence

- Patient, carer and family centred care is a historical cornerstone of palliative and end of life care.
- It leads to improved quality of life physical and psychological (Temel et al 2010; Temel et al 2017).
- Studies show that aligning health care around the preferences and needs of patients can improve patients' satisfaction with their care and their clinical outcomes.
- Patient-centered care reduces both underuse and overuse of medical services. (Agency for Healthcare Research & Quality)

Education and shared knowledge

- **Communities** need an increased understanding of the need for and benefits of quality care for people approaching and reaching the end of their life.
- Through community engagement and awareness raising, death and dying will be more openly discussed by more people outside of crisis events.
- Death is considered a natural event and will be increasingly de-stigmatised

Education and shared knowledge

- Patients, families and carers are well-informed about their illness and treatment options.
- Goals for patient, family and carer are defined and appropriately documented.
- Advance care planning is undertaken, documented and regularly reviewed
- The preferred place of care and death is articulated and documented.

Involvement of family and friends

- **Patients, carers, families** have a key role in contributing to decisions about care and are considered as 'partners' in the provision of health care.
- People's needs change.
- The needs of the patient, family and carer during their end of life journey vary over time and care settings.

Collaboration and Team Management

- Negotiated goals of care guide service provision to prioritise quality of life for patients, their families and carers.
- Clinical staff are able to identify those people who may benefit from integrated care as they approach the end of life.
- People have an opportunity through early recognition to benefit from enhanced care models.
- Liaisons and partnerships are built with other specialists and services to provide multidisciplinary care.

Sensitivity to non-medical and spiritual dimensions of care

- Integrated care is “the provision of seamless, effective and efficient care that responds to **all of a person’s health needs**, across the domains of physical, mental, social and spiritual in partnership with the individual, their carers and family.
- Practical support services may be needed. Carer fatigue may need to be addressed
- Actively encourage discussion of disease impact on relationships, social life, family
 - Do you worry about being a burden to others?
 - Do you worry about how your family will cope without you?

Sensitivity to non-medical and spiritual dimensions of care

- Spiritual distress may present as physical or psychological and it shares many features with depression – feelings of hopelessness, worthlessness and a sense of meaninglessness. It may exacerbate or be exacerbated by physical symptoms for example pain.
- Cultural, spiritual and other values of patients, their families and carers are respected
- Psycho-social and spiritual support is available and offered.
- Access to grief and bereavement support is available and offered.

Respect for patient needs and preferences

- People are able to receive care that meets their goals as they move between settings of care (i.e. hospital, home, aged care).
- These goals need to be negotiated and agreed with patients and their families
- Care is well coordinated and support is provided to patients, carers and families to assist in navigating health and community care systems.

Free flow and accessibility of information

- Clinical information is available at the point of care in all care settings.
- Terminology is clearly articulated and understood
- Clinicians across all settings know when and how to access specialist palliative care services.
- Ongoing access to specialist palliative care services is based on regular assessment of need and adapts to these accordingly.
- Liaison and coordination with other specialists occur

Conclusion

- A fundamental principle of palliative care is that patients and their families receive support in their experiences of illness, care-giving and grief and that these experiences are inseparably linked.
- In principle, the individual, their family and the palliative care team of doctors, nurses and allied health staff work collaboratively to clarify treatment preferences, values and goals which are built on the development of trust and respect.

Conclusion

- Communication is the key

