

Comprehensive and compassionate care in palliative care: findings of an ethnographic study

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Palliative care in Indonesia



- Started in 1990's^{1,2}
- Need of PC for cancer patient → 69.31-145.73 /100,000 population³

Palliative care in Indonesia



- Group 3 level 1 → isolated PC service provision^{3,4}
- Palliative care policy in 2007⁵
- Six hospitals: four in Java, one in Bali, and one in Sulawesi⁹
- Two non-government organisations (NGOs): Indonesian Cancer Foundation and Rachel House⁶



Palliative care in Indonesia?

Aims

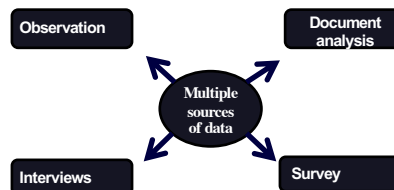
To explore the provision of formal palliative care services for cancer patients in Indonesia

Objectives

- To describe the structure, model of care delivery of PC
- To identify cultural elements which influence the provision of PC
- To explore views and experiences of patients and families about PC service

Methodology

- Ethnography
- Multiple data sources:



Data collections

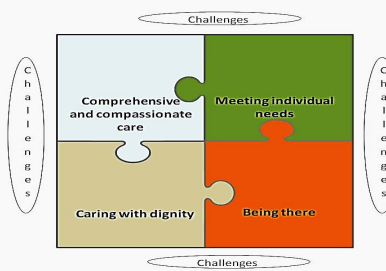
- Two palliative facilities in Jakarta
- January – March 2014
- Data collections: observations, interviews, survey and document analysis



Major cultural domains

- The provision of care: challenges and accomplishments
- Building relationships
- Family care giving
- Spiritual and religious practices
- Death and funeral

The provision of care: challenges and accomplishments



.....After assessing the patient, the doctor told the relatives that there were coarse rattling sounds in her lung (rhonchi). The doctor explained to the patient's husband that the sound was caused by secretions in the lung and required a nebuliser procedure to release the secretions. The husband nodded in agreement for the procedure. The doctor asked the nurse to administer a nebuliser and to show the procedure to the patient's husband. The nurse demonstrated the nebuliser procedure. The husband observed and listened carefully to the nurse.

(Field notes on 20 Feb 2014 p.83:L31-34; p.84:L5-9, L17-24, L31-33)

At that time, the patient had several blisters on both arms and a pressure ulcer on her back. The nurse assessed the wounds and then commenced wound care. When the patient's husband explained that he changed the wound dressing every day, the palliative team suggested only doing it once every 2-3 day unless the dressing leaked. During the wound care, the patient's husband helped to hold the patient so she was able to stay lying on her side. The nurse used the opportunity to explain several wound care tips to the patient's husband such as using a particular powder to reduce the odor and using double dressings to prevent leakage.

(Field notes on 20 Feb 2014 p.83:L31-34; p.84:L5-9, L17-24, L31-33)

Comprehensive and compassionate care

- Concerns to current symptoms and made them as priorities for interventions
- Including relatives in the care process and decision making

Comprehensive and compassionate care

- Comprehensive: physical, psychological and spiritual
 - physical: based on the patient's symptoms and needs
 - psychological: verbal and physical, simple to complex strategies

When the palliative doctor performed an assessment on a patient in one typical out-patient palliative consultation, the patient began to cry. Knowing this the palliative nurse closed the door the palliative unit for providing more privacy to the patient. The palliative doctor stopped her assessment, maintained eye contact with the patient, showed concern and gently stroked the patient's back. This had a very positive impact on the patient. Once the patient was calm, the palliative doctor continued to do the assessment.

- spiritual: perform prayers together, work with the local chaplaincy

Comprehensive and compassionate care

Compassionate care

'a care that centred on the relationship of the palliative team and those in their care'

- The palliative team showed their compassion through care explicitly recognised the suffering and the hardship experienced by the patients and their relatives
- The palliative team were aware of individual needs and genuinely provide care to meet these needs which resulted in the patients'/relatives' comfort

Comprehensive and compassionate care

Strategies to provide compassionate care:

- Addressing fundamental care needs → provided in a timely manner

For instance, a patient was shivering after some interventions. The palliative team responded by providing several blanket and giving warm fluids. Eventually, the patient felt better and more comfort after all these interventions.

- A willingness to have a fully engaged relationship based on a good communication

Comprehensive and compassionate care

Strategies to provide compassionate care:

- A willingness to have a fully engaged relationship based on a good communication
- ✓ Making sure the family had sufficient information about the patient's conditions
- ✓ Providing the family with practical instructions and information for caring the patient
- ✓ Responding well to any questions by doing more assessment and providing sufficient answer

Comprehensive and compassionate care

Strategies to provide compassionate care:

- A willingness to have a fully engaged relationship based on a good communication

For example, in a typical home visit, the palliative team explained to the family including the patient's conditions, prognosis, possible palliative interventions, aims of palliative care and practical instructions to care the patients. The family looked really satisfied with the information and trust the palliative team, ...*'Regarding my wife's treatment, I really trust you (the palliative team)'...* *'if there are other treatment planned by the primary doctor, I will consult with you first'*. Clearly, the family had great trust to the palliative team in providing the care .

Comprehensive and compassionate care

Strategies to provide compassionate care:

- A willingness to have a fully engaged relationship based on a good communication
- ✓ Introducing themselves
- ✓ Tailoring communication to suit with the patients' cultural background
- ✓ Prompt response

For instance, in several occasion, the palliative team responded promptly when the patient's relatives contacted them either by phone, texting or email. This strategy resulted positively as the relatives were satisfied and had more trust with the palliative team

References

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Thank You

Questions?