Hospice philosophy in practice

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STUDY AIM

The study aims to gain understanding of how hospice philosophy works in everyday practice at contemporary Danish hospices.

BACKGROUND

This study examines how hospice philosophy works in contemporary Danish hospice practice. The first Danish hospice opened in 1992 and today there are 20 hospices which are integrated in the public healthcare system. The still sparse literature on Danish hospices indicates that hospice philosophy is influencing professional practice. In international palliative care literature hospice philosophy is challenged for being overly normative or on the other hand as threatened by the medical model. Drawing on the idea of hospice philosophy as providing meaning for everyday practice the study explores how hospice philosophy is incorporated within the institutional order of contemporary Danish hospices.

METHODS

An ethnographic study was informed by seven weeks of participant observation and 49 interviews with professionals, patients and families at three hospices in different regions of Denmark. Data was collected May 2017 – February 2018. The fieldwork involved participant observation of activities such as staff meetings, routine practices and daily activities plus conducting interviews with patients, relatives and staff.

FINDINGS

Six themes were identified as essential for hospice practice:

1 OPEN AWARENESS OF DYING

Open awareness of dying is guiding practice as an ideal adapted to the specific context.

There is no recipe, it is not that they have to lie 'upright' in bed in an acceptance of a hospice-like picture of the good death

2 PAIN RELIEF AND PEACEFUL BODIES

Holism was incorporated in practice as an awareness of the whole body's suffering including not only targeting specific symptoms but also helping the dying person to be reestablished as a social body.

It might sound banal in this context of hospice care but basically pain relief is about taking care of the whole. It is not only that the patient is in pain, physically. It is about the total pain (nurse)

3 FEELING SAFE

A relational approach to dying understood as a shared responsibility for the dying person and family permeated the atmosphere at the hospices.

I am a stubborn person and have been used to managing my husband's care myself. But they (the staff) saw through me and sneaked their care in through the back door so that I can let go. They are wiser than me – I need to let go but I couldn't. (wife to a patient)

4 'HOSPICETIME'

Enough clock-time, timing and presence created a peaceful atmosphere and focus on each individual patient.

The reason why I appreciate this job so much is because I have enough time to talk with the patients. There is no fixed time schedule and if needed the conversation can continue later. (medical doctor)

5 HOMELINESS

A shared approach was directed towards creating an atmosphere of existential belonging in which the dying could feel 'home' as social beings despite the unknown state of dying.

Hospice, one could say, is a place of faith, hope and love because everybody can be themselves. It is as if the masks are left behind outside the door. (volunteer)

6 CHALLENGES TO HOSPICE PRACTICE

Hospice practice has to co-operate/compete with other ideals for practice such as evidence–based practice (EBP) and managerial strategies. EBP in the form of quantitative assessment tools does not always sit easily with the more narrative and holistic hospice philosophy. For example all the hospices use the questionnaire EORTC-QLQ-C15-PAL as a tool for assessing quality of life (DMCG-pal 2017).

I think that I am inhibited in creating a relationship. A lot of them experience it as a kind of exam having to respond to, on a scale from 1 to 4, am I short of breath. (...) when I meet a patient it is about making him feel that here we take care of you. (nurse about the use of EAPC)

Towards an authentic death

The findings illustrate hospice practice as ongoing maintenance of hospice philosophy. Maintenance work involved adapting hospice philosophical ideals of a good death such as open awareness and acceptance of dying to the patients' own position. Also a holistic approach to pain relief was adapted to patients' lived lives. Hospice practice aimed at creating hospice as a safe and homely space for the dying and families. Hospice practice works towards delivering a 'good death' by means of ongoing interpretation work directed towards authentic dying. As such hospice philosophy does not define the good death but delivers an institutionalized vocabulary related to death and dying that is adapted to individual needs and wishes.

CONCLUSION

The results of the study reinforce the relevance of hospice philosophy in Danish hospice practice as a "lived" philosophy which works as an interpretive practice to sustain an authentic death rather than being a set of fixed institutionalized values. An "authentic death" as a possible ideal for hospice philosophy is our, albeit tentative, suggestion of an interpretive approach to the question of the good death. Within a healthcare system with an increased focus on measurable evidence for practice and demands for efficiency, maintaining hospice philosophy as a fundamental guide for practice is challenging. To maintain its place it is necessary to both articulate and also to prioritize the ethos of hospice philosophy. The identified challenges to hospice practice are the tensions related to evidence based practice and managerial strategies and point to the need for further research to explore how such tensions might be reconciled within the reflexive framework of hospice practice.

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