Introduction

Much attention has been given in recent years to the concept of illness trajectories and their potential use in the planning of services provided to those with life limiting illnesses. This study examines how trajectories are experienced by bereaved individuals and whether the memories retained by the bereaved or their experience of grief differ according to the disease trajectory of the deceased.

Background

Rapid demographic change over the past 150 years; we now tend to live longer and die more slowly from chronic disease. Increasing difficulty in predicting death and the dying phase. Grief now seen not as a series of stages to be worked through but as a ‘state of being’. (Field 2003)

Emphasis on ‘continuing bonds’ between the deceased and the bereaved. (Valentine 2008)

Changing memorial practices, ‘from cathedral to supermarket’, ‘from words to silence’. (Walter, 1996, 2001)

Evolution of palliative care and desire to expand it’s ethos and practice beyond those with cancer diagnosis. (DoH, 2008)

Methods

• One to one unstructured in depth interviews conducted with bereaved relatives and staff members between three months and two years after the death.
• Thematic analysis of the narratives produced.
• Mapping of trajectories of dying from relatives and health professionals perspectives.

Preliminary Results

Trajectories: Lack of uniformity or ‘fit’ of trajectories. Some marked differences between accounts given by staff and relatives. Importance of ‘normality maintenance’ in the face of trajectories. Key events recounted by relatives are not necessarily related to medical status of deceased. Fluidity of awareness of dying.

Memories: Importance of planned and spontaneous memory making activities and forward acts of remembrance. Shared and communal memories as a source of support and comfort. Shaping and justifying of memories in order to achieve continuity and fit between the dying trajectory and prior biography of the deceased.

Bereavement: Need to achieve a ‘good’ or ‘appropriate’ death as defined by the deceased - sacrifices made by the bereaved in order to achieve this. Importance of Health Care Professionals in recognising trajectories, legitimising and enabling access to services. The continued presence of the deceased.

Discussion

Accounts illustrate a wide variety of remembered experience and some marked differences between ‘official’ and remembered trajectories. The ‘good death’ is assessed in relation to the wishes and habits of the deceased rather than any external concept or scheme. This leads in some cases to a disparity of need between deceased and carer as efforts are made to enable the deceased to remain in control of all aspects of their lives and to approach their illness as they choose.

The input of Health Care Professionals is welcomed and viewed as vital by the bereaved as providing information, access and endorsement of choices.

References


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