

To Grieve Or Not To Grieve?

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Information needs of patients with cancer in UK (n=2331)

- 87% of all information good and bad
- 98% preferred to know if they had cancer

Jenkins, Fallowfield and Saul (2001) British Journal of cancer 84 (1):48-51

Anticipatory Grief

.... normal mourning...when a patient or family is expecting a death.

Many of the same symptoms as those experienced after a death.

All of the thinking, feeling cultural and social reactions to an expected death ...felt by the patient and family.

The grief experience before a death does not make the grief after the death last a shorter amount

(eMedicine Health)

...Individuals readiness to die does not appear to be age dependant-

Older patients are not more accepting of death than younger people.

...Combination of physical, psychological, social and family factors appear to play the most significant role”

(Lichter&Hunt1990, Licter 1991, Twycross&Licter 1993)

Time Frame Affecting the Adjustment Process

- **The shortest and longest periods of anticipation were associated with poor outcomes**
 - Short prognosis of 6 months
or
 - Longer period of 18 months had a negative effect on adaptation to impending death.
 - Mean time of 12 months appeared to assist the families adapt to impending loss.
- Rando (1983) and Sanders (1982:83)

Patient:

59 year old , retired one year when diagnosed with AML.

- Remission for 6 weeks after first treatment cycle.
- 10 week admission for flag treatment, refractory to same.
- Currently on experimental treatment for the past 2 months.
- Family composition:married with two adult children

Three Levels of Analysis

1. **Psychological** –

1. Take into account the particular coping abilities, beliefs, feelings and other psychological characteristics of the bereaved.

2. **Interpersonal** –

1. Type of relationship that is being grieved,
2. The manner in which the principals deal with or deny their grief,
3. The type of support they receive for coping with it, will profoundly affect its experience.

3. **Sociocultural** –

1. The norms, roles and rituals available to the bereaved.
2. Anticipatory grief will be influenced by the presence or absence of norms, roles and rituals for the griever.

(Fulton and Gottesman 1980's)

“The best way that I can describe what my family and I are going through is similar to being on Death Row...”

(Lady, 52yrs, refractory AML)

**“It is like being given a death certificate
though you are still alive...”**

(Lady, 57 end stage multiple myeloma)

Influencing factors

- Loss of self
 - important concern expressed by the patient
- Sadness and grief
 - in response to the losses accompanying disease progression and physical deterioration
- Expression of grief
 - related to previous, current and anticipated losses

(Cobb 1999)

Anticipatory Grief has three time foci Loss.....

- 1 **Past**- ...shared and can never be regained.
- 2 **Present**- ... that occur and are experienced as an erosion of capabilities...
- 3 **Future**-...of the anticipated death and such as loneliness and events that *will not* be shared.

(Rando 1986. Gilbert 1996-2007)

‘...everyone has to die of something...’

“... one of the good things about those illnesses (such as cancer) that enables us to predict when a person will die is that they give the family of the dying person time to prepare themselves for the event....

...one of the bad things is that the family often fail to take this opportunity”

(Parkes et al 1996:100)

“we should do all in our power to ensure that
.... people whose lives will be affected by a
death are warned of the danger and are
given any emotional support that they need
in order to come to terms with it..”

(Parkes 1996)

Denial

1. Denial of the primary facts of the illness
2. Denial of the clinical significance or implication of the illness
3. Denial that the illness will end in death

Denial is an interpersonal as well
as an intrapersonal process

Disagreement of the professional view is ***not necessarily denial.***

- Someone who has a view that prayer/positive attitude etc would bring about a cure *is not always in denial*. They have just a *different view of how the world works* from the doctor.
- It does not dent the dying persons convictions and that of the relatives that it was possible for prayer/positive attitude to be affective in such situations-even if it does not turn out to be.

(Sheldon 1997)

Four tasks of anticipatory grief

- 1 To satisfy bodily needs and **minimise physical distress** in ways that are consistent with other values
- 2 To **maximise psychological security**, autonomy and richness in living
- 3 To sustain and **enhance those interpersonal** attachments and to address the social implications of dying
- 4 To identify, develop or reaffirm sources of **spiritual energy** and in so doing foster hope

(Corr 1991-1992)

What works?

- Information that is clear, factual and delivered in an supported and appropriate manner
- Good social support
- Open communication [team, patient & family]
- Listening
- Quality of life (time frame)
- Patients and families that engage with the support that is being offered (practical and emotional etc)

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TAKE HOME....

- Be aware...
- Educate your team
- Support patient & family.