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Effects of euthanasia on the bereaved family and friends: a cross sectional study

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Abstract

Objective To assess how euthanasia in terminally ill cancer patients affects the grief response of bereaved family and friends.

Design Cross sectional study.

Setting Tertiary referral centre for oncology patients in Utrecht, the Netherlands.

Participants 189 bereaved family members and close friends of terminally ill cancer patients who died by euthanasia and 316 bereaved family members and close friends of comparable cancer patients who died a natural death between 1992 and 1999.

Main outcome measures Symptoms of traumatic grief assessed by the inventory of traumatic grief, current feelings of grief assessed by the Texas revised inventory of grief, and post-traumatic stress reactions assessed by the impact of event scale.

Results The bereaved family and friends of cancer patients who died by euthanasia had less traumatic grief symptoms (adjusted difference -5.29 (95% confidence interval -8.44 to -2.15)), less current feeling of grief (adjusted difference 2.93 (0.85 to 5.01)); and less post-traumatic stress reactions (adjusted difference -2.79 (-5.33 to -0.25)) than the family and friends of patients who died of natural causes. These differences were independent of other risk factors.

Conclusions The bereaved family and friends of cancer patients who died by euthanasia coped better with respect to grief symptoms and post-traumatic stress reactions than the bereaved of comparable cancer patients who died a natural death. These results should not be interpreted as a plea for euthanasia, but as a plea for the same level of care and openness in all patients who are terminally ill.

Introduction

Grief is a normal reaction to the death of a loved one and normally does not require any professional help. Traumatic grief refers to situations where grief symptoms take too long or too short, are too intense or not intense enough, or come too late.¹ Depending on

the definition, 10-20% of bereaved people will suffer from traumatic grief.

Sudden loss, loss of a child or a partner, low self esteem, low internal control, lack of religion or spiritual belief, lack of social support, low education, and young age have been identified as risk factors for developing traumatic grief.² Unnatural death, such as suicide, can cause severe grief reactions in family members.³ As euthanasia is also considered as an unnatural death, it has been suggested that euthanasia may induce traumatic grief.¹ However, the grief experienced by family members in suicide cases differs from grief after euthanasia, mainly because the relatives of the latter have had the opportunity to "say goodbye," which is seldom the case in suicides.⁴

In the Netherlands euthanasia is carried out on about 3200 people a year, of whom 80% have cancer.⁵⁻⁶ The aim of this study was to examine the effects of euthanasia in terminal cancer patients on grief among bereaved family and friends.

Participants and methods

Study population

We conducted a cross sectional study among the bereaved families and friends of cancer patients who had died, either by euthanasia or natural causes, in the University Medical Center Utrecht between 1992 and 1999. Euthanasia was defined as "the intentional termination of the life of a patient at his or her request by a physician."⁶⁻⁷ This definition excludes termination of life without the request of the patient, as well as alleviation of pain and other symptoms with drugs that finally hasten the patient's death. For each patient who died by euthanasia, we selected two control patients from all cancer patients who died from natural causes in our hospital during the same period. We matched control patients by age at death, by year of death, and by sex. During 1992-9, 95 patients died by euthanasia in our hospital, of whom 89 were oncology patients. We were unable to contact the bereaved family and friends of 11 of these 89 patients. We therefore selected 156 control patients from the 1360 oncology patients who died naturally in our hospital during the same period.

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The study population consisted of bereaved people who were immediate family members (partner, parent, child, or sibling) or friends who were with the patient at the moment of death, were informed about the cause of death, were aged 18-85 years, and were fluent in Dutch. We sent a questionnaire to all potential participants a week after sending them a letter giving information on our study.

Measurements

Between January 2000 and August 2001 we sent questionnaires to all participants. The questionnaire contained, beside demographic items, seven standardised questionnaires assessing grief symptoms, post-traumatic stress reactions, general wellbeing, depressive symptoms, and personality as well as a general questionnaire we composed about several aspects of the period of the patient's death.

We assessed grief with a Dutch version of the inventory of traumatic grief (ITG), a 29 item, self completed questionnaire with a high score indicating a greater risk for traumatic grief,⁸ and with the second subscale of the Texas revised inventory of grief (TRIG), which consists of 13 items and measures current reactions to loss with high scores representing less current grief symptoms.⁹ We measured post-traumatic stress reactions with the impact of event scale (IES), a high score indicating more post-traumatic stress reactions.¹⁰ We assessed general wellbeing with the symptom checklist (SCL-90), a high score indicating less general wellbeing.¹¹ We assessed depressive moods with a Dutch version of the depressive adjective checklist (DACL), with a high score indicating more depressive symptoms.¹² We assessed participants' personality with the generalised self-efficacy scale (SES), which measures self confidence,¹³ and with the Eysenck personality questionnaire (EPQ-RRS),¹⁴ of which we used the part that measures neuroticism.

Results

Our results are based on returned questionnaires of the bereaved relatives and friends of 58 of the 78 patients who died by euthanasia and 114 of the 156 control patients who died naturally (table 1).

Of the 264 questionnaires we sent to the bereaved relatives and friends of cancer patients who died by euthanasia, 197 were completed and 189 (72%) had less than 10% missing values. Of the 480 questionnaires sent to bereaved family and friends of the control patients, 392 were completed and 316 (66%) had less than 10% missing values. The family members who did not complete the (whole) questionnaire or did

not respond were more likely to be male than those who responded (51% *v* 43% male), and they did not differ in their kind of kinship with the dead patient.

The relatives and friends of the euthanasia patients were less religious than the family and friends of the control patients, and their level of education was higher. Their relationship with the patients also differed: the family and friends of euthanasia patients consisted more of the subgroup defined as others (such as cousins, in-laws, or friends), whereas the family and friends of control patients consisted of more children and siblings (see bmj.com for details).

Table 2 shows the differences in grief symptoms, post-traumatic stress reactions, general wellbeing, and depressive symptoms between the bereaved relatives and friends of euthanasia patients and those of control patients. For all questionnaires except the Texas revised inventory of grief a high score means more symptoms or complaints. We found a small but non-significant difference between the groups for the symptom checklist (relatives and friends of euthanasia patients scoring somewhat better on general wellbeing), and both groups scored similarly on the depressive adjective checklist. However, the relatives and friends of euthanasia patients had significantly lower scores on the inventory of traumatic grief and impact of event scale score and higher scores on the Texas revised inventory of grief. The percentage of bereaved people who fulfilled the criteria of traumatic grief was twice as high in the control group as in the relatives and friends of euthanasia patients (5.7% *v* 2.1%), indicating that there was a clinically significant difference as well as a statistically significant one.

Educational level, the score on the Eysenck personality questionnaire neuroticism scale, and kinship were the most important confounders of the association between cause of death and grief symptoms and post-traumatic stress reactions. After adjustment for these factors, euthanasia was still associated with less severe symptoms and reactions. Adjustment for all other potential determinants for traumatic grief did not change these findings (table 2). However, adjustment for "saying goodbye" to patients considerably weakened the association between cause of death and grief symptoms or post-traumatic stress reactions (table 2).

Discussion

In this cross sectional study, the bereaved families and friends of cancer patients who died by euthanasia had less grief symptoms and post-traumatic stress reactions than the families and friends of comparable cancer patients who died from natural causes.

The consequences of euthanasia on grief among the bereaved family and friends have been described by Van den Boom, who interviewed 60 relatives of 52 AIDS patients who had died.¹⁵ Twelve of these patients had died by euthanasia. He found no significant association between the prevalence of depression in the bereaved family and friends and the way of death. However, he did find that a complicated euthanasia process was associated with complicated grief and added distress to the bereaved family and friends. In our study complications in the euthanasia process did not occur; situations like that are more likely to occur when euthanasia is performed at home.¹⁶ To our

Table 1 Characteristics and medical history of 58 cancer patients who died by euthanasia in the University Medical Center Utrecht between 1992 and 1999 and 114 control cancer patients who died from natural causes. Values are numbers (percentages) unless specified otherwise

Characteristics	Cause of death	
	Euthanasia (n=58)	Natural death (n=114)
Female	37/58 (64)	70/114 (61)
Mean (95% CI) age at death (years)	61 (58 to 64)	62 (60 to 64)
Geometric mean (95% CI) length of illness (months)	15 (10 to 22)	10 (7 to 13)
Cancer untreatable at first diagnosis	8/58 (14)	23/114 (20)
Geometric mean (95% CI) period between date questionnaire sent out and date of death (months)	35 (29 to 43)	39 (34 to 43)

Table 2 Differences between the relatives and friends of 58 cancer patients who died by euthanasia in the University Medical Center Utrecht between 1992 and 1999 and of 114 control cancer patients who died from natural causes in scores for grief, post-traumatic stress reactions, general wellbeing, and depressive symptoms. Values are means (95% confidence intervals) unless stated otherwise

Questionnaire	Mean (95% CI) scores by cause of death		Difference (95% CI)*			
	Euthanasia (n=189)	Natural death (n=316)	Crude	Adjusted for education, EPQ, and kinship with patient	Adjusted for all†	Adjusted for opportunity to "say goodbye"‡
Inventory of traumatic grief	39 (38 to 41)‡	45 (43 to 47)‡	-7.05 (-10.64 to -3.45)	-5.54 (-8.95 to -2.12)	-5.29 (-8.44 to -2.15)	-5.51 (-9.29 to -1.73)
Texas revised inventory of grief	46 (44 to 48)	42 (41 to 43)	3.57 (1.23 to 5.91)	2.60 (0.27 to 4.92)	2.93 (0.85 to 5.01)	2.77 (0.31 to 5.24)
Impact of event scale	13 (11 to 15)	18 (16 to 19)	-4.78 (-7.66 to -1.89)	-3.74 (-6.54 to -0.94)	-2.79 (-5.33 to -0.25)	-3.14 (-6.09 to -0.19)
Symptom checklist	116 (111 to 120)	121 (118 to 125)	-5.62 (-11.83 to 0.59)	-2.43 (-6.93 to 2.07)	-1.61 (-6.29 to 3.08)	-2.46 (-9.0 to 4.08)
Depressive adjective checklist	9 (8 to 10)	9 (9 to 10)	-0.04 (-0.92 to 0.84)	0.34 (-0.42 to 1.10)	0.40 (-0.39 to 1.19)	0.40 (-0.53 to 1.32)

EPQ=Eysenck personality questionnaire.

*Differences obtained by multilevel regression analysis, 95% confidence intervals calculated with robust standard errors.

†Adjusted for: education, EPQ score, kinship with dead patient, age, sex, self efficacy score, religion, support of bereaved, depression of dead patient, patient's age at death, patient's length of treatable illness, patient's duration of illness, period between questionnaire and patient's date of death, adequate pain treatment for patient, adequate treatment of gastrointestinal complaints for patient, other complaints of patient, and whether the cancer was treatable at time of diagnosis.

‡Geometric mean.

knowledge, this is the first study on the association of euthanasia in patients with terminal cancer and the grief symptoms in family members.¹⁷

Limitations of study

Non-response may have influenced our findings. However, the responses from the relatives of the patients who died by euthanasia were somewhat higher than that from the relatives of patients who died naturally (75% *v* 69%). People with greater feelings of grief are more prone to non-response than persons with less feelings of grief.¹⁸ Therefore, the differences we found are probably an underestimation rather than an overestimation from non-response. It is also possible that the contact people for the dead patients selected only those relatives and friends for the study who were coping well, so that those with more severe grief symptoms may not have been invited to participate. However, it is unlikely that this would be different for relatives of patients who died from natural causes and thus cannot explain our findings.

In the Netherlands many patients die at home (40%), especially oncology patients (48% of all cancer deaths).¹⁹ Our study population may therefore not be representative of relatives of all dead oncology patients. It is possible that people experienced death and bereavement in hospital in a different way than the relatives of cancer patients who died at home. We therefore have to restrict the interpretation of our findings to patients dying in hospital.

Extraneous factors that were not within the scope of this study might explain the differences we found between the two groups. For example, terminally ill patients who request euthanasia may have a different personality from those who do not, and this difference may also hold for their family members. We tried to take this into account by controlling for neuroticism, but other personality factors may have influenced the results.

Another difference between the two groups of patients surely must have been the capacity to acknowledge their prognosis. Since prognostic denial is most likely to arise in patients with underlying distress,²⁰ and distress will have a negative effect on the wellbeing of the bereaved family and friends, this might also explain the differences between the two groups.²¹ Moreover, Chochinov also found an association between intense family contact and prognostic

What is already known on this topic?

In the Netherlands 3200 patients die by euthanasia each year, and 80% have terminal cancer

The grieving process by friends and relatives can be long and painful, but the effect of euthanasia on this process has not been studied

What this study adds

Grief after the death of a terminally ill cancer patient by euthanasia was not more complicated for the family members than grief after a natural death

Having the opportunity to say goodbye to the patient may be an important determinant of grief and post-traumatic stress reactions

awareness. A possible explanation for our results is that family members may have colluded with the prognostic denial of deeply distressed patients in the group that died of natural causes. This may have had a detrimental effect on the grief process of these family members afterward.²² There is a need for open awareness of impending death and for careful and thoughtful planning for where and how the death ought to occur.²³

Conclusion

Possible explanations for less grief symptoms among the bereaved family and friends of cancer patients who died by euthanasia are: (a) the opportunity to say goodbye while these patients were generally still fully aware, an interpretation that our results support; (b) the bereaved family and friends of these were probably more prepared for the way and day of the imminent death; and (c) when a terminally ill patient requests euthanasia, family members and the patient are often able to talk openly about death. Our results should not be interpreted as a plea for euthanasia, but as a plea for the same level of care and openness in all patients who are terminally ill.

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A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas

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Abstract

Objective To identify the palliative care needs of terminally ill people in Uganda.

Design Descriptive cross sectional study.

Setting Home care programmes in and around Kampala that look after terminally ill people in their homes.

Participants 173 terminally ill patients registered with the home care programmes.

Results Most of the participants had either HIV/AIDS or cancer or both; 145 were aged under 50 years, and 107 were women. Three main needs were identified: the control or relief of pain and other symptoms; counselling; and financial assistance for basic needs such as food, shelter, and school fees for their children. The preferred site of care was the home, though all these people lived in urban areas with access to healthcare services within 5 km of their homes.

Conclusion A "good death" in a developing country occurs when the dying person is being cared for at home, is free from pain or other distressing symptoms, feels no stigma, is at peace, and has their basic needs met without feeling dependent on others.

Introduction

The epidemic of HIV/AIDS has stretched the already poorly resourced healthcare infrastructure in sub-Saharan Africa, including Uganda. Access to basic

health care is limited to only 41% of the population.¹ Annual expenditure per capita stands at just \$12 (€10, £7), and 34% of the population live in absolute poverty (living on or earning less than \$1 a day and unable to afford enough food to consume 2000 to 3000 calories a day).¹

Nearly all terminally ill patients die in their own homes under the care of their families, having been discharged from hospital as their diseases have no cure. Little is known about the care they receive or how they die. Palliative care, especially end of life care, is still new in Uganda. It was introduced in 1993 by Hospice Africa (Uganda). There is overwhelming demand for care for the dying but inadequate funding. I carried out this study to identify the palliative care needs of those dying at home in an attempt to improve their quality of life up to the time they die. Participants were drawn from home care programmes in and around Kampala. These programmes were started by non-governmental health services to help in the home care of bedridden people with HIV/AIDS and cancer.

Methods

This descriptive cross sectional study was carried out from January to April 2000 in Kampala district. The study population included all 320 people who were terminally ill with either cancer or HIV/AIDS, or both, and were bedridden at home and registered with any one of the home care programmes in Kampala. Using the formula for simple random sampling for single