Dying cancer patients talk about euthanasia

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ABSTRACT

Within developed nations, there is increasing public debate about and apparent endorsement of the appropriateness of euthanasia as an autonomous choice to die in the face of intolerable suffering. Surveys report socio-demographic differences in rates of acceptance of euthanasia, but there is little in-depth analysis of how euthanasia is understood and positioned within the social and moral lives of individuals, particularly those who might be considered suitable candidates—for example, terminally-ill cancer patients. During discussions with 28 such patients in Australia regarding medical decisions at the end of life, euthanasia was raised by 13 patients, with the others specifically asked about it. Twenty-four patients spoke positively of euthanasia, 19 of these voicing some concerns. None identified euthanasia as a currently favoured option. Four were completely against it. Endorsement for euthanasia was in the context of a hypothetical future or for a hypothetical other person, or temporally associated with acute pain. Arguments supporting euthanasia framed the issue as a matter of freedom of choice, as preserving dignity in death, and as curbing intolerable pain and suffering, both of the patient and of those around them. A common analogy featured was that of euthanising a dog. These arguments were typically presented as self-evident justification for euthanasia, construed as an appropriate choice to die, with opposers positioned as morally inferior or ignorant. The difficulties of ensuring ‘choice’ and the moral connotations of ‘choosing to die,’ however, worked to problematise the appropriateness of euthanising specific individuals. We recommend further empirical investigation of the moral and social meanings associated with euthanasia.

Introduction

Within democratic industrialised nations, discussion regarding medical assistance in attaining death has achieved increasing momentum, beginning in the 1970s and showing no signs of abating (Dowbiggin, 2002). These nations share a number of characteristics: access to sophisticated medical infrastructures, substantial proportions of the populations living beyond 70 years and dying from degenerative or chronic diseases characterised by sustained periods of medical intervention and a gradual decline in function (Battin, 1991). These democratic nations also take autonomy to be the pre-eminent value in medical practice, asserting the rights and responsibilities of the individual to determine their medical treatment, and to refuse treatment even when this might result in their death (Emanuel, 1998). Simultaneously, individuals expect that the medical profession will ensure a comfortable death (Charmaz, 1980). The combination of these factors has prompted conclusions that the current focus on euthanasia is the logical consequence of cultural assumptions that doctors are obliged to ensure that patients die in circumstances that are acceptable to them (Dowbiggin, 2002).

Euthanasia, however, means different things to different people (Nilstun, Melltorp, & Hermeren, 2000; Parkinson et al., 2005). It is often subcategorised into active vs. passive
(which refers to the provision or not of specific medical treatments) and voluntary vs. non-voluntary vs. involuntary (which refers to the degree to which the wishes of the one dying are known and determinative) (Ardelt, 2003). Although a commonly accepted definition refers to ‘a doctor intentionally killing a person by the administration of drugs, at that person’s voluntary and competent request’ (Materstvedt et al., 2003: 98) or active voluntary euthanasia, lack of agreement regarding definition has been noted as complicating accurate assessment of the practice of, and support for, euthanasia (Ho, 1998; Nilstun et al., 2000). In addition, ‘euthanasia’ sometimes includes the provision of pain relief to the point of terminal sedation, otherwise known as the principle of double-effect (Quill, Lo, & Brock, 1997). Critically, although some treat these practices (excluding involuntary euthanasia, deemed homicide) as practically and morally equivalent (e.g., Magnusson, 2002; Quill et al., 1997), others do not (e.g., Materstvedt et al., 2003; Somerville, 2003).

There is a voluminous medical literature debating the pros and cons of either practicing, or legalising, euthanasia (Nilstun et al., 2000). As debate encompasses ethical, medico-technical, legal, and social claims, for and against euthanasia (Ardelt, 2003; Brock, 2000; Sanson et al., 1998; Somerville, 2001), comprehensive coverage is beyond the scope of this article. Dominant arguments for euthanasia center on patient autonomy and well-being (Brock, 2000): those against, on the value of life, and potential impact of euthanasia on medical practice and society as a whole (Hermsen & ten Have, 2002; Sanson et al., 1998).

Although the amount and quality of empirical data lag behind academic debate (Sanson et al., 1998), survey or opinion polls suggest that there is increasing public support for euthanasia. A recent survey of 33 European countries found highest level of support in countries espousing the right to self-determination (Cohen et al., 2006). In the United States, more than two-thirds of the population reportedly favour euthanasia (Duncan & Parmelee, 2006), and in Australia (the site for this study), a poll conducted while the current study was underway suggested that approximately 75% of Australians find euthanasia to be acceptable in some form (Morgan, 2002).

Questions have been raised, however, regarding the validity of survey results assessing euthanasia support, with studies showing variation dependent on the precise wordings and definitions used (Cartwright, Williams, Parker, & Steinberg, 2006; Parkinson et al., 2005). Some writers have observed that opinions that ending suffering is a worthwhile goal and that patient autonomy should be paramount may not equate to support for legalising euthanasia (Cartwright et al., 2006; Johansen, Holen, Kaasa, Loge, & Materstvedt, 2005). Others note that abstracted attitudes may not reflect actual behaviours when faced with a personal choice in the here-and-now (Dowbiggin, 2002; Ho, 1998; Sanson et al., 1998).

Other studies estimate the incidence of euthanasia (again, often plagued by inconsistencies in definition), and correlation studies report on the characteristics of those supporting or requesting euthanasia (e.g., Breitbart et al., 2000). Interestingly, the dominant reason given in support of euthanasia is to avoid intractable pain in the terminally ill (Emanuel, Fairclough, Daniels, & Clarridge, 1996), yet psycho-social factors appear as important in the decision-making of persons involved (Ardelt, 2003; Suarez-Almazor, Newman, Hanson, & Bruera, 2002).

These findings are echoed by qualitative analyses of interviews with terminally-ill patients, typically concentrating on cancer patients’ attitudes towards, or reasons for and against, euthanasia (e.g., Johansen et al., 2005; Kuuppelomaki, 2000). Terminally-ill cancer patients are usually identified as most likely candidates for euthanasia (Kuuppelomaki, 2000) and, where it is legally permissible, most likely to be euthanised (Haverkate et al., 2000; Kissane, Street, & Nitschke, 1998). In a Norwegian study based upon interviews conducted with 18 terminally-ill cancer patients (Johansen et al., 2005), the authors reported that a positive attitude towards euthanasia did not equate to a personal desire to die, and that patients’ wishes for euthanasia typically referred to a hypothetical possibility in the future, usually associated with a fear of future, but not current, pain. During an ethnographic study of 30 cases of euthanasia in the Netherlands, Pool (2000) found considerable variation in practice, as decisions emerged in the course of multiple, seemingly idiosyncratic interactions between patients (most with AIDS or cancer), families, doctors, and nurses. There were, moreover, multiple and sometimes contradictory interpretations made by all parties about individual acts of euthanasia, during processes leading up to, and after, the patient’s death.

These writers and others have stressed the need to further examine the assumptions underpinning professed attitudes, and the significance of surveys of patient and public opinion (Johansen et al., 2005; Mak, Elwyn, & Finlay, 2003; Pool, 2000). Such calls are echoed by those observing the importance of language in discussions about euthanasia (Pool, 2000; Somerville, 2003).

In a previous study examining how Australian cancer patients (not considered close to death) talked about the decision not to resuscitate following cardiac arrest (the ‘do-not-resuscitate’ or ‘DNR’ decision), we observed that many patients mentioned euthanasia. Some equated DNR issues with euthanasia and some considered a lack of hope as legitimate grounds to perform euthanasia (Elliott & Olver, 2003). At the time, events within Australia had brought the euthanasia debate to renewed public attention.

In July 1996, the proclamation of the Rights of the Terminally Ill Act (RTI Act) saw the Northern Territory of Australia as the first and only place to allow individuals to access euthanasia lawfully. Nine months later, the Australian Federal Parliament amended the legislative powers of the Australian Territories (Euthanasia Laws Act, 1997), prohibiting legislation on euthanasia, thus overturning the RTI Act. During its operation, there was extensive media coverage regarding five of the seven people who applied to die under its terms, four achieving their aims (see Mcinerney, 2006; Street & Kissane, 2001, for analysis of Australian media accounts). Despite the repeal of the RTI Act, euthanasia legislation has been proposed since in various Australian states, without success (Kerridge, Lowe, & McPhee, 2005): euthanasia remains illegal.

During the present study, there was considerable media coverage regarding Nancy Crick who, following her
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