Reading between the lines: analysis of free text responses to assisted dying consultation

Last year, the RCP reasserted its position on assisted dying via a survey of its membership. **Professor Albert Weale**, chair of the RCP's Committee on Ethical Issues in Medicine, and **Dr Aude Bicquelet** analyse the free-text responses of survey respondents to get a clearer view of members' feelings.

In 2014 the RCP surveyed its members on proposed legislation on assisted dying. In addition to questions about whether they supported a change in the law, what the RCP's position should be and whether they would be prepared to participate actively in assisted dying, participants were also given the opportunity to provide free-text responses. We analyse these responses here to see what these responses reveal about the attitudes of RCP members and fellows and the reasoning behind their responses.

New developments in computer-aided text-analysis make it much easier to analyse free-text responses. Our approach rests on looking at associations between the same words appearing in different sentences. We can group sentences together into classes depending on how words co-occur in different respondent sentences, in which all sentences are grouped together, and then divided into two groups that are as distinct as possible.

The positions of different types of respondents can be defined by the characteristic sentences they use. For example, if acute specialists use the term 'palliative care' disproportionately, that group will be associated with the class in which the term 'palliative care' defines the class. The whole process is purely formal: classification of the co-occurrence of words in sentences is a syntactical operation that can be thought of, in effect, as a very efficient filing system. Whether the resulting classes can be given meaning is a matter of interpretation.

Results

Our analysis grouped the free-text responses to the consultation into seven well-defined classes (table). Class 1 is straightforward and includes words associated with the procedure of the consultation itself. The words in this class often related to matters such as whether the respondent should state an opinion or not – perhaps because they are retired. Words related to the substantive issues occur in the other six classes, which fall into three main groups: one comprising classes 2 and 4, words used by those who are largely opposed to change; one comprising classes 6 and 7, used by those in favour of change; and one comprising classes 3 and 5, an intermediate group who raised issues that cut across the debate.

Largely opposed to change

Class 2 predominantly contains statements of those who are opposed to legislative change, with one of main reasons for opposition being that the elderly might feel pressured or have a sense that they were being a burden on others. This class is strongly positively associated with those against change. 'I feel that any change in the law will be a slippery slope and that it will result in many people feeling vulnerable, especially those who already feel a burden to their families and on the provision of health care,' was the response of one palliative medicine specialist indicative of the characteristic patterns of reasoning for respondents associated with class 2. Unsurprisingly, palliative care specialists, GPs, rehabilitative medicine, geriatrics and ophthalmology were all strongly represented in this class.

Although the risk of untoward effects of a legislative change are usually mentioned in general terms, there was some discussion of particular experience in other jurisdictions. 'There is ample evidence of incremental extension and mission creep in other jurisdictions like Belgium, Oregon and the Netherlands,' said one respondent in this class. 'While I am unconvinced by the pressure on the vulnerable argument, I do think that there is evidence, from Dutch experience, of a slippery slope,' added another. But others whose vocabulary also fell into this class contested this view: 'The evidence, from Oregon and elsewhere, shows that the slippery slope counter argument has no validity. There is no reason to suppose that the introduction of assisted dying in the UK would be substantially different in impact.' However, some participants in favour of change were also included in class 2, as a result of emphasising the duty of physicians to ensure that feelings of being a burden or external pressures do not affect patients' consideration of assisted dying.

Class 4, meanwhile focused on physicians' duties, and the predominant claim was that assisted dying is contrary to the ethos of the physician, with several references to the Hippocratic oath ('Physician-assisted suicide is against our entire purpose of a doctor of above all do no harm'). There is also a worry that some patients will lose faith in their doctor: 'The medical profession must distance itself from harming patients in this way. If we become involved in killing patients, this will irreversibly damage the trust between patient and doctors.' There was an association between general stance on legislative change and the lack of willingness to participate personally.

But again, not all respondents in class 4 were opposed to change. One in favour of change made the point that this was a social decision: 'This should be a decision for the whole of society and not one solely for the medical profession. If passed there should be no compulsion/duty for doctors to undertake this who are opposed on moral/religious grounds'. In a similar vein, the comparison was made with abortion also by someone in favour of physician-assisted suicide.

Varying views were expressed about the personal role of the doctor by respondents in class 4, with some thinking they would be unable to 'administer a medication that [they] knew would kill a patient' and others arguing that physicians are 'the most likely to possess the knowledge and techniques to assist'. However, several respondents opposed to change said that they would leave the profession if the change were brought in.

Finally, some drew attention to possible pressures on medical professionals if the change were made: 'My reluctance to accept this legislation is not due to any moral objection. My concern is for protection for medical staff against complaint/ litigation. Doctors will be left vulnerable no matter how tightly the legislation

is drafted.'

In favour of change

Respondents grouped into classes 6 and 7 are weighted towards favouring legislative change, although the association between overall position and vocabulary is not as strong as that for classes 2 and 4. Respondents in class 6 typically expressed their support for legislative change on the basis of the experience of watching patients or relatives undergo a prolonged and painful terminal illness. However, other respondents use their personal experience to come to the opposite conclusion: 'The last patient to request [assisted dying] actively from me lived 2 years from the request and ended up doing active volunteering work with various groups from his request.'

Other common views in this class were that there is a lot of uncertainty surrounding prognosis, which is a reason to be cautious about a change in the law; that advanced directives should become more common; and that the days of 'doctor knows best' are over. One geriatrician distinguished 'letting die' from 'active killing', but said that the practice of letting die is often not understood. A common theme – implicit and sometimes explicit – in the statements in this class is that medical care in the NHS does not deal well with terminal illness.

The vocabulary in class 7 was the most significantly associated with the views taken on changes in the law. Typical arguments in this class related to favouring assisted suicide in terms of the avoidance of suffering for the terminally ill, or the best interests or rights of the patient ('I would dearly love to be able to help those who do want to die it grieves me, and is a profound source of stress in my job, to see patients suffering unbearably, in their own opinion, but to be unable to help them'). This is also the class in which discussions of dignified death occur. Those in favour of legal change also express scepticism about the extent to which palliative care can deal with all cases of serious pain and discomfort.

On the fence?

Classes 3 and 5 contain responses less clearly associated with contrasting positions in the debate. Class 3 contains a large number of comments on palliative care – the need for improvements and proper financing ('Unfortunately palliative care does not provide the degree of effectiveness its proponents suggest and I suspect never will'), scepticism about effectiveness or suitability (also seen in class 7 responses), the inadequacy of community care ('Unfortunately the necessary community and secondary care support isn't available') etc.

Class 5 words are related to the complexity of legislating on and implementing assisted dying, as well as the guidance that would be needed. Some of those against change think that the difficulty of drafting legislation containing adequate safeguards precludes change ('Of course assisted dying happens but I think it is impossible to legislate for in a way that is not open to abuse'). By contrast, those in favour of change draw attention to the need for safeguards – ie that change ought to be conditional on adequate safeguards ('Key to my support would be the safeguards. Personally, I do not believe a panel of 2 doctors is sufficient'). Some say that a legislative change would make for more individual decision-making.

Table: Classes from descending classification

Data in parentheses indicate the proportion of the total sentence number that each class comprises.

	Predominant interpretation
Class 1 (9%)	A distinctive class focused on the process of consultation itself.
Class 2 (15%)	A class overwhelmingly giving reasons for opposing any change in the law, based on danger to the vulnerable if assisted dying is allowed. Virtually all respondents in this class answered 'no' to questions 1 to 4.
Class 3 (18%)	A class focused on the role of palliative care. Although most of the sentences used by people in this favoured improvements in such care, some also highlighted difficulties.
Class 4 (19%)	A class focused on the role of the physician, and in particular giving reasons why that role is incompatible with the practice of assisted dying, though with some qualification.
Class 5 (16%)	A class highlighting the complexity of legislating in this area, with the complexity highlighted by both those in favour and those against the change.
Class 6 (10%)	A class highlighting the distress of patients with a painful or lingering death, disproportionately coming from those in favour of change.
Class 7 (13%)	A class giving reasons for being in favour of assisted dying on the basis of the interests, rights or dignity of the dying, disproportionately coming from those in favour of change.

Discussion

The pattern displayed in the classification of responses shows how those on different sides of a debate stress different features of a complex situation – a common occurrence. Physicians opposed to assisted dying focused on the vulnerability of patients and the ethical obligations inherent in medicine, while those in favour honed in on cases of insoluble pain and suffering caused in some cases of terminal illness, and the need to respect the rights and wishes of patients. Other studies of similarly contentious moral questions in policy debate suggest ownership of different dimensions of a complex issue is common. How far people talk past one another varies from case to case.

In their different ways, respondents grouped into classes 2, 4, 6 and 7 expressed sincere and deeply held views and values. Such views are typically slow to change and are not easily susceptible to counter-argument. Even when the same subject is being referred to, it can be viewed the different ways, as exemplified by the fact that respondents on both sides of the debate referred to abortion law reform to support their argument. However, our analysis suggests that there are issues that are in principle susceptible to empirical research and evidence, and which could affect participants' opinions:

1. How far technically is palliative care able to deal with hard cases? Are shortcomings a product of inadequate practice, or are they cases where even the best practice is inadequate?
2. What would be the funding implications of seeking to secure best practice in palliative care?
3. Has legalisation of assisted dying in other jurisdictions led to a slippery slope?
4. Is it feasible to suppose that a set of rules could be written governing the practice in which patients, the public and professionals had confidence that all legitimate interests are protected?

Assisted dying is a topic on which reasonable people will take different views. Discussion of such complex topics can be helped by identifying the questions on which empirical evidence reduces inter-subjective disagreement. On the basis of the free text responses, the RCP might wish to consider whether investigation of these four questions could shed further light on the discussion.