

RESEARCH REPORT:

Implementing an Assisted Dying Bill

Findings from
focus groups with
doctors and **nurses**



CAMPAIGN FOR
DIGNITY
IN DYING.

APRIL 2016

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I feel it would be of benefit to a small minority of patients who have a terminal illness and who actually would benefit from passing away peacefully rather than continuing to suffer for an indeterminate amount of time

GP

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Dignity in Dying commissioned YouGov to conduct focus groups, with the explicit purpose of exploring with doctors and nurses how the Assisted Dying Bill would work in practice.

The findings indicate that doctors and nurses widely agree that palliative care cannot relieve all suffering for all dying people and they are sympathetic to dying people who want to end their lives. Most participants agreed that doctor involvement is crucial when assessing eligibility and it was suggested that the medical world provides the safest and most patient-centred environment for assessment.

Doctor and nurses' informed input is essential and provides the basis for further developing the safest and most workable law. For example, participants discussed the time needed to engage with a requesting patient and assess their eligibility; would they be given protected time to assess a patient's eligibility and what training would be provided? Interestingly, whilst some viewed the length of time it takes to assess a patient as positive, because it means the patient would have detailed discussions, others viewed the time-factor as a barrier to working. Participants also expressed that the BMA does not reflect the range of its members' views through its current position.

The findings of these focus groups suggest there is an appetite for a similar approach to be taken by other professional organisations. This process also highlights the need for clear and accurate information to move the debate forward.

Background

In July 2015, **Dignity in Dying** commissioned YouGov to conduct two focus groups, with the explicit purpose of exploring with medical professionals how the Assisted Dying Bill would work in practice. Participants were provided a copy of the Bill alongside detailed data from Oregon including numbers of people requesting medication, numbers having an assisted death, their reasons for doing so, time to unconsciousness and time to death. This allowed the doctors and nurses to examine the proposed model set out in the Assisted Dying Bill (that is, a law limited to terminally ill people with doctor involvement in diagnosis and assessment of eligibility and provision of life-ending medication) and data on how it functions in practice (1). This resulted in professionals being given the opportunity to voice their informed judgements and feelings about the potential implementation and impact of assisted dying legislation.

Since we commissioned the focus groups, the BMA has published its report on the dialogue events they commissioned (2) which examined perceptions of assisted dying amongst doctors and patients. Those dialogue events focused on the perception of how the doctor-patient relationship may be affected by different types of assisted dying laws, including models neither proposed nor debated in the UK. The dialogue events also gathered opinion on some aspects of assisted dying in Oregon, such as medical complications, having presented participants with selected data.

We are publishing our findings to share what clinicians feel are the practical implications of the assisted dying model that has been proposed and debated in the UK. This is for two primary purposes. The first is to add to the debate around assisted dying amongst doctors and compliment the findings from the BMA's research. Secondly, it is to demonstrate how important it is to engage clinicians in practical and evidence-based dialogue on assisted dying, rather than debating hypothetical laws and incomplete evidence.

We hope that, in publishing these findings, the BMA, its members and the public can see the valuable role doctors and patients play in considering proposed laws in practice and providing constructive suggestions on how they might be delivered and implemented.

It is important to note that assisted dying is illegal in the UK and for many care professionals the issue is relatively unknown and unexplored. It is no surprise therefore that there remains misunderstanding of what a law would look like and how patients could be assessed for eligibility. As yet there has been little opportunity for professionals to discuss the procedure as set out in the Assisted Dying Bill and feed back on what works and might not work from their perspective. These focus groups set out to start addressing this gap and we hope the findings will influence future debate.

Levels of support amongst doctors for assisted dying

Whilst it was neither a subject of this research or the BMA's research, evidence shows that care professionals throughout the UK hold a wide range of views on the issue of assisted dying (3, 4). This is recognised by the BMA. However, so far, debates have tended to focus on looking at yes/no support and ethical concerns untethered from detailed knowledge of the proposed law change in the UK or of comparable working laws overseas.

Methodology

Dignity in Dying commissioned YouGov to run two online focus groups in July 2015. This methodology is effective for exploring difficult topics and providing a space where participants can air their views freely. YouGov provided an analysis of the focus groups, which has formed the basis of this report.

The first focus group was made up of 10 GPs and the second was made up of 10 specialist nurses or doctors who reasonably might be expected to care for dying people. Both groups contained only participants who were moderately supportive, neutral or moderately opposed in principle to assisted dying; ensuring that a measured debate about the detail of what was proposed,

rather than the principle of it, took place.

Participants were given the 2015 Assisted Dying Bill, as debated in the House of Commons, in advance; alongside a summary of the process, reports and statistics from the Oregon Health Authority (who audit the Death with Dignity Act), together with peer-reviewed research and polling on public and GP support. This meant that participants could consider their views on the process in advance, allowing them to focus on the mechanics of the assisted dying model. It was important to take this approach, rather than conducting research which focussed primarily on how different assisted dying models and laws may be (mis)understood.

Key Findings

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1. *Palliative care cannot relieve all suffering*

There was an acknowledgement that palliative care cannot relieve all suffering. Care professionals are sympathetic and expressed feeling sad that someone would go to Dignitas. Some concern was also shown about people going earlier than they may have otherwise chosen to, so cutting their life shorter than necessary.

‘For the best available palliative care people still appear to suffer’

Nurse

‘I think it is a bit sad that only the ones who have the money are able to do that [go to Dignitas]’

GP

‘I think it is sad that people have to potentially end their life earlier than they would like to because they have to be fit enough to travel to Switzerland independently’

Nurse

2. *Supporting a patient who requests assistance to die*

Based on evidence from Oregon and detail on the proposed model for England and Wales, overall participants expressed a range of views on whether they would feel confident enough to support a patient who requested assistance. No participants stated that they would refuse to talk about the issue with a requesting patient, however some participants shifted positions during the discussion and there was a sense they would feel more confident once other care professionals had assessed patients and the practice had ‘bedded-in’.

‘I feel there should be a change in the law, but as to what that is, I’m not sure’

Nurse

‘My views have changed more towards assisted dying as I have gained more experience as a doctor and GP...seeing the inhumane life that some patients end up leading...not even being able to die when they want to’

GP

‘Supportive to change in the law so patients can make decisions [about] what is best for them’

GP

'There are some definite cases where humanity would suggest that pointless suffering is inhumane and that a dignified end to life is a marker of a caring society'

GP

'I hope that it doesn't get passed, but expect that it will, and would be happy to work with it, as it would be part of my responsibility towards a patient'

GP

'I support the discussion in public of the issues around this topic. I wouldn't myself wish to be directly involved but would advise any of my patients who expressed a wish to die on how to access the process'

Registrar

'It sounds hypocritical as I am supportive of a law allowing assisted dying but I wouldn't want to personally be involved. The decision has to be 100% correct and there would always be doubt at the back of my mind'

GP

'I feel very torn between people's right to autonomy and not to suffer, but me not feeling comfortable being involved in ending someone's life and people choosing it for the wrong reasons'

Nurse

3. *Care professionals think the BMA should be neutral on assisted dying*

Participants viewed the BMA as being out of touch and not reflecting the range of views of its members. There was some consensus that a Bill would not be passed given the current position of the BMA and some Royal Colleges. Discussion on this issue echoed a 2015 poll of 1,000 GPs which found 56% supportive of medical bodies being neutral on the issue of assisted dying, with only 20% believing they should be opposed (3).

'I would have thought more would expect the BMA to be neutral given the range of views'

Nurse

'Very conservative really... probably concerned about opening a hornets nest'

GP

'The BMA are a doctors union and should focus their efforts accordingly'

Doctor

'...doesn't alter my own personal views or concerns as don't feel that any of these bodies really represent me.'

GP

4. *The assisted dying model – doctor involvement*

When presented with the Assisted Dying Bill and evidence from Oregon, there was overall consensus that medical professionals should be central to the process of assessing a patient's request and little support for them sitting entirely outside of this. Participants suggested different models of doctor, care professional, independent person and judicial involvement. However a process which incorporates all of these is already set out in the Assisted Dying Bill.

Doctor involvement

Overall, there was strong support for the medical profession to be involved in the assisted dying process and no participants suggested that the medical profession sit entirely outside. There was consensus that patients need ongoing support from doctors and that only trained professionals can diagnose and suggest appropriate care. To a lesser extent however, there was the suggestion of a specialist service or panel for assessing requesting patients. Doctors were seen as being key to supporting patients and families, prescribing drugs, assessing capacity etc.

'Why should it be outside of the medical world?

The family need the support of their GP and local service provision [...] Depends what you mean by outside the medical world – do you mean lawyers? Surely they would need prescription drugs?'

GP

'The patient needs the support of caring professionals throughout their illness and if they choose to shorten its natural duration. They are the people trained to care for them to the end'

Oncologist

'I think the medical world allows for professionals with experience in capacity and the disease to be involved. I can't see how it would be safe for this to be done elsewhere'

Cardiologist

'You need a medical person to check the medical condition and validate the request and appropriateness of it. A lay person could not do this, chance of error and doing it wrong'

GP

'Yes, I think a medical professional needs to write the prescription.... I think the numbers of patients would be small, in life and death, a doctor should do the prescription, with legal planning'

GP

Involvement of other care professionals

The majority of participants were in agreement that a range of care professionals – for example psychiatrists or social workers - should be involved in assessing eligibility. Concerns over assessing capacity or needing a specialist team were raised. The assisted dying model goes some way to address these concerns by suggesting the assessing doctors draw on the expertise of specialists and includes the stipulation that an independent (or second) doctor also assesses the patient for eligibility.

[when discussing who would be involved in the assessment of a requesting patient] ‘Legal professionals obviously but also if say a social worker was involved. I just feel it would help to have someone non-medical involved’

Nurse

‘An independent person is essential as a precaution – perhaps similarly to how a medical capacity advocate works’

Cardiologist doctor

‘I think this would need to be a specialist area and would involve a lot of time and resources and thus I think anyone becoming involved in making these decisions would have to be specially trained in the law around this area’

GP

'I suspect for this work [we] will need to have a group of people who are experienced in this and not just for everyone to try to get involved'

GP

'...seems pretty clear, up to the bit about capacity. I would foresee problems in deciding if any associated depression had been treated or attempted to have been treated'

GP

'It would have to be a specialist who would need to assess capacity'

GP

Judicial involvement

Participants were broadly supportive of judicial oversight (or at least not opposed), but questioned a judge's role. Some participants viewed this as a rubber-stamping exercise and one participant challenged if having a judge was necessary if it is a legal process anyway. However, there was an overall feeling that this might make doctors more comfortable with the process. This is an example of where ongoing care professional input is needed to ensure that a change in the law is both workable and safe.

'Might just be a rubber-stamping exercise as the judge wouldn't know about capacity and prognosis and be able to be certain that all the facts are correct, but this would be a safeguard for the GP'

GP

‘Does the judge rely on medical capacity assessment or does another person complete that for the courts?’

Nurse

Specialist service model

There was some discussion about the process being led by a specialist service. However, this needs to be taken onboard within the context of training and support being available for doctors.

‘I think a specialist service is what is needed...not just a “have a go” GP doing it once a year’

GP

‘I think it needs to be a specialised service with a few nationwide doctors assuming responsibility for these requests’

GP

‘The terminal diagnosis and six-month prognosis as proposed have to come from within medicine. The rest of the process could occur without’

Nurse

5. *Time to assess eligibility*

A number of participants raised concerns about the time needed to engage with a requesting patient and assess their eligibility. Whilst some viewed the time needed to assess a patient as a strength and safeguard (i.e. time allows it to be done thoroughly), others couldn't get past this as a practical concern. These concerns would be addressed in a code of practice and demonstrates the need for further care professional involvement in drafting legislation and implementation guidance.

'This bill gives you as the patient plenty of time to consider what you are doing, no quick hasty decisions, plenty of time to back out, and you can arrange things to have them ready until you feel ready'

Nurse

'It is a big deal. How quickly does it work, it would be a long visit, very emotive. You would have to set aside a couple of hours, which we don't have'

GP

'Sounds awful but this would be so time consuming that it may prevent busy doctors and professionals from getting involved'

GP

6. *Need for training*

As with any medical procedure, participants suggested that training would be needed. Alongside this, some concern was expressed about the low numbers of requesting patients and how this might mean they would be inexperienced as practitioners in assessing requesting patients.

‘Whilst I think the numbers are small my concern is I won’t have the experience to deal with it as it is not that frequent’

GP

‘Yes – I would feel inexperienced and like I did not know as much about it as I should’

GP

7. *Oregon figures – misunderstandings*

There is a mismatch between actual figures from Oregon and expectations of numbers by participants. The low numbers of assisted deaths in Oregon, and that 40% of patients go through the process but do not take the life-ending medication, was a surprise to many participants who were expecting numbers to be higher. That 40% didn’t take the medication was viewed positively as an example of choice providing psychological comfort.

‘Surprised also that only 60% in Oregon who get the drugs will use them. Maybe it is the reassurance that the drugs are there would reduce anxiety’

GP

8. *Defining quality of life and 'bleakness' of prognosis*

There was some debate around what makes one prognosis different from the other in terms of predictability and impact on the patient. Some terminal conditions were viewed as being particularly bleak and therefore, as care professionals, they may feel more comfortable with the choice of assisted dying for this group of patients. This theme warrants further exploration and input from care professionals.

'For certain conditions e.g. MND, the path is bleak, and fear of choking/ not being able to breathe, terrifying. Why wait?'

GP

'Beneficial for patients with good prognosis in terms of time but horrible prognosis in terms of quality of life e.g. MND, etc. Perhaps not so beneficial for cancer patients

GP

Conclusions

The findings indicate that doctors and nurses widely agree that palliative care cannot relieve all suffering for all dying people and they are clearly sympathetic to dying people who want to end their lives. There was also discussion that the choice of assisted dying brings comfort to many people who do not go on to have an assisted death, which was viewed positively by participants. This suggests that when armed with evidence, care professionals understand how a change in the law would not bring about a “duty to die” in their patients.

Most participants agreed that doctor involvement is crucial when assessing eligibility and it was suggested that the medical world provides the safest and most patient-centred environment for assessment. The need for an independent person to oversee the process and specialist expertise on capacity and prognosis to be involved was raised by participants, all of which are safeguards incorporated in the Assisted Dying Bill. This suggests a gap in knowledge (which was also highlighted in the BMA’s research) and, to an extent, validates the current model.

Recommendations for practice raised by the groups suggest that doctor and nurses’ informed input is essential in order to make the safest and most workable law. For example, some doctors and nurses expressed concern about the time that would be needed to engage with a requesting patient and assess their eligibility. Would they, for example, be given protected time to assess a patient’s eligibility and what training would be provided? Interestingly, whilst some viewed the length of time it takes to assess a patient as positive (the patient would have detailed discussions and evaluation), others viewed the time-factor as a barrier. This area needs further exploration.

Similarly, judicial oversight (which is a relatively new addition to the process) was neither viewed positively or negatively. Rather it was something that generated debate around what the role of judges would be, demonstrating the need for clarity and further exploration of how this additional safeguard might bring support and comfort to care professionals.

Participants expressed that the BMA does not reflect the range of its members' views through its current position. Clearly, representative organisations' input is needed to contribute to the development of a law that works for dying people and those that care for them.

Findings from the focus groups like these are only part of the solution for developing a law that works in practice. For any law to be effective there needs to be parliamentary scrutiny which examines the detail of the Bill and associated evidence, alongside proper debate and engagement of relevant care professionals and the public.

Evidence from the BMA's research on the perceptions of assisted dying are useful in highlighting the gaps in knowledge, demonstrating that clear and accurate information is needed for the debate to move forward.

In October 2015 assisted dying was legalised in California, with the California Medical Association (CMA) dropping its opposition earlier on in the year as a result of a “*shift in the conversation*” (6)

A shift in position by the CMA has resulted in them producing guidance on both assisted dying and wider end-of-life care (7), an approach which not only contributes to the development of a workable model of assisted dying, benefiting both patients and care professionals, but an approach which accurately reflects the diverse views of its members.

The findings of these focus groups suggest there is an appetite for a similar approach to be taken by professional organisations in this country. The BMA and Royal Colleges must ensure they are doing everything possible to enable them to contribute to the assisted dying debate in a constructive and impartial manner.

1. <http://www.publications.parliament.uk/pa/bills/cbill/2015-2016/0007/16007.pdf>
2. BMA (2015) End-of-life care and physician-assisted dying: reflections and recommendations
3. Medeconnect (2015)
4. Seale C (2009) Legalisation of euthanasia or physician-assisted suicide: survey of doctor's attitudes Palliative Medicine 23: 205-12
5. <http://www.bma.org.uk/support-at-work/ethics/bma-policy-assisted-dying>
6. <http://www.reuters.com/article/us-usa-assisted-suicide-california-idUSKBN0052T120150520>
7. <http://www.cmanet.org/news/press-detail/?article=california-medical-association-issues-guidance>