OFFICIAL REPORT
AITHISG OIFIGEIL

Health, Social Care and Sport Committee

Tuesday 19 November 2024

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

Tuesday 19 November 2024

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HEALTH, SOCIAL CARE AND SPORT COMMITTEE

33rd Meeting 2024, Session 6

CONVENER

*Clare Haughey (Rutherglen) (SNP)

DEPUTY CONVENER

*Paul Sweeney (Glasgow) (Lab)

COMMITTEE MEMBERS

*Joe FitzPatrick (Dundee City West) (SNP)
*Sandesh Gulhane (Glasgow) (Con)
*Emma Harper (South Scotland) (SNP)
*Gillian Mackay (Central Scotland) (Green)
*Carol Mochan (South Scotland) (Lab)
*David Torrance (Kirkcaldy) (SNP)
*Elena Whitham (Carrick, Cumnock and Doon Valley) (SNP)
*Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Amy Dalrymple (Marie Curie Scotland)
Mark Hazelwood (Scottish Partnership for Palliative Care)
Dr Iain Kennedy (BMA Scotland)
Fiona McIntyre (Royal Pharmaceutical Society)
Dr Sarah Mills (University of St Andrews)
Rami Okasha (Children’s Hospices Across Scotland)
Colin Poolman (Royal College of Nursing Scotland)
Dr Chris Provan (Royal College of General Practitioners Scotland)

CLERK TO THE COMMITTEE

Alex Bruce

LOCATION

The Alexander Fleming Room (CR3)

Scottish Parliament

Health, Social Care and Sport Committee

Tuesday 19 November 2024

[The Convener opened the meeting at 09:01]

Decision on Taking Business in Private

The Convener (Clare Haughey): Good morning and welcome to the 33rd meeting in 2024 of the Health, Social Care and Sport Committee. I have received no apologies.

We continue our scrutiny of the Assisted Dying for Terminally Ill Adults (Scotland) Bill at stage 1. By virtue of rule 12.2.3(a) of the Scottish Parliament's standing orders, Liam McArthur MSP, the member in charge of the bill, may attend the meeting if he wishes.

The first item on our agenda is to agree to take agenda item 4 in private. Do members agree to do so?

Members *indicated agreement.*

Assisted Dying for Terminally Ill Adults (Scotland) Bill: Stage 1

09:01

The Convener: The next item on our agenda is to take evidence from two panels of witnesses as part of our scrutiny of the Assisted Dying for Terminally Ill Adults (Scotland) Bill at stage 1. We begin by hearing evidence from organisations representing the healthcare professions, in order to consider the impact on and implications of the bill for their members.

I welcome Dr Iain Kennedy, chair of the British Medical Association Scottish council; Fiona McIntyre, policy and practice lead, Scotland, at the Royal Pharmaceutical Society; Colin Poolman, executive director of the Royal College of Nursing Scotland; and Dr Chris Provan, chair of the Royal College of General Practitioners Scotland.

We will move straight to questions, beginning with Carol Mochan.

Carol Mochan (South Scotland) (Lab): I thank the witnesses for joining us and will begin by talking about the bill's definition of "terminally ill". I am sure that people will have read that the bill's current definition refers to having

> "an advanced and progressive disease, illness or condition from which they are unable to recover and that can reasonably be expected to cause their premature death."

While taking evidence, we have heard mixed opinions of that definition. Based on your knowledge and experience, what do you think of the definition? Is there another definition that you would like to refer us to or do you have views on what should be added to, or taken from, that definition? I am happy to hear from the witnesses in any order.

Dr Chris Provan (Royal College of General Practitioners Scotland): I am a general practitioner working two days a week in a practice in Aberdeen, so I have experience of palliative care.

Our organisation is opposed to a change in the law on assisted dying, but I will look today at the broad range of views within our member organisation and will try to represent those as I consider the practicalities of the bill and its implementation.

The definition is not one of the areas that we have significant concerns about, because it appears to cover much of what is relevant and is relatively narrow, without giving a timescale. I do not have much to say against it, but it is important that we do not get a change in that definition over time without having a review of the situation, as may have happened in some other countries.

Carol Mochan: Do other witnesses want to come in? That would be helpful.

Colin Poolman (Royal College of Nursing Scotland): People know that the Royal College of Nursing has a neutral position on the proposals and has had such a position for a number of years.

I do not want to comment on the definition because I would not want any comments to be misconstrued. We have not had deep conversation with our membership about that.

Fiona McIntyre (Royal Pharmaceutical Society): The Royal Pharmaceutical Society holds a neutral stance on the principle of assisted dying. We have not examined the definition of “terminally ill” in the bill and do not hold a position on that.

Dr Iain Kennedy (BMA Scotland): Good morning. Since September 2021, the BMA has taken a position of neutrality on assisted dying. That means that, in my position as chair of BMA Scotland, I represent the view that the BMA neither supports nor opposes a change in the law. However, any change in legislation would have a significant impact on doctors, so BMA Scotland has a responsibility to protect and represent all our members. That includes all doctors and medical students.

The BMA has not discussed eligibility and the definition of “terminally ill” but we have looked at the bill and have a problem with the word “premature”, which is ambiguous. Normally, the word “premature” would be used to mean—

The Convener: We will move on to other parts of the bill and other members have questions, so please stick to the question that Carol Mochan asked.

Carol Mochan: Is there another definition of “terminally ill” that the BMA would use in other areas of medicine?

Dr Kennedy: Off the top of my head, I cannot remember the BMA ever discussing it, so I think that the answer to your question is no.

Carol Mochan: Your answers to my other question might be similar to those that you have just given. Have any of your organisations discussed with your membership the age limit of 16 years old that is in the bill?

Some legal experts have talked about safeguarding but, in some other areas, under 16-year-olds are deemed competent to make decisions about healthcare. Have any of your organisations discussed that?

Dr Kennedy: No, the BMA has not discussed the age criterion and, specifically, the difference between Scotland and the rest of the United Kingdom in relation to the age of 16.

Colin Poolman: We have not discussed that but we have discussed the implications, because that is what the college has considered. If there were a limit of 16 years and upward, it would mean that many more health professionals would be involved. That is the only aspect that we have considered.

Dr Provan: The Royal College of GPs has not specifically discussed the age limit of 16. Those who are opposed to a change in the law have concerns about vulnerable patients. That was the highest concern. There are also concerns about a fundamental shift in the relationship between doctors and patients, supporting palliative care and capacity, which we might come on to but which fits into discussing including 16-year-olds to some extent. However, we have not taken a specific view on the age limit.

Gillian Mackay (Central Scotland) (Green): Is there enough clarity in the bill on whether assisted dying would be considered a reasonable treatment option?

Dr Kennedy: Could you ask the question again, please?

Gillian Mackay: Is there enough clarity in the bill on whether assisted dying would be considered a reasonable treatment option?

Dr Kennedy: The BMA’s position is that assisted dying should not be regarded as a conventional treatment option.

Gillian Mackay: In some foreign jurisdictions, such as in Victoria in Australia, doctors are restricted from initiating discussions about assisted dying, with patient autonomy often emphasised as being the reason for that. At the opposite end of the spectrum, doctors in Canada are allowed to raise the option proactively. In your opinion, what would be the most appropriate approach to ensure informed decision making in Scotland without undermining patient autonomy? Should the bill explicitly include an obligation to ensure access to assisted dying, if the bill were to be passed?

Dr Kennedy: The BMA’s position is that doctors should have the right not to discuss assisted dying but that they should also not be penalised in any way for raising the issue. We want doctors to be protected, whether they wish to raise the issue or decide not to do so. Both aspects must be explicitly provided for.

Dr Provan: We are very clear that doctors must have the ability to opt out of involvement in such situations and that they should not have to justify why they do not wish to be involved. That must be balanced against access for patients, if there is a service. The key thing is to have conversations about the range of services available to patients, so that they are aware of palliative care and of all the options.

I emphasise the need for doctors to be able to opt out. We may come on to that subject: we are in favour of having an opt-in system and creating an infrastructure where there is time to have those conversations with people who have experience of them.

Colin Poolman: I am sure that we will move on to consider an opt-in system. Access to information, both for patients and practitioners, is important and that must be independent information. We would be very keen to see that provided, if the bill goes forward, so that people have independent access to information and can make informed decisions, which will take the pressure off individuals.

Fiona McIntyre: Although the bill includes pharmacists in the meaning of “health professional”, the role of pharmacists is unclear and the bill says only that pharmacists are one of the three professions that can accompany an authorised practitioner at the time of an assisted death. The role of pharmacists is not described in the bill, apart from that single mention of them accompanying the authorised practitioner.

The Convener: I have a quick supplementary question, which is probably for Colin Poolman, so I place on record that I am currently registered with the Nursing and Midwifery Council and have a bank nursing contract with NHS Greater Glasgow and Clyde.

Colin, you spoke specifically about medical staff. Nursing staff play a huge role in multidisciplinary teams, particularly in in-patient settings, but also in community settings. What consideration has the Royal College of Nursing given to the involvement of nursing staff in those conversations?

Colin Poolman: We believe that there should be an opt-in system and that people who wish to support assisted dying should be able to opt in. I am absolutely sure that we will come to that idea.

That takes us back to the issue of not putting undue pressure on professionals to have such conversations, because some people will feel very uncomfortable about that. That goes beyond the idea of conscientious objection because some people might find it mentally harmful to have that discussion, which is why it is our view that there should not be a duty on people to have those conversations.

09:15

Emma Harper (South Scotland) (SNP): I remind everybody that I am still a registered nurse. My background is in perioperative care.

Colin Poolman mentioned conscientious objection, so I will put this question to him to begin with. Is there enough clarity as to which staff and activities would be covered by the conscientious objection section in the bill, which comprises only two subsections? What are your thoughts on that?

Colin Poolman: We do not feel that there is enough clarity on that. The inclusion of conscientious objection is important, of course, but the bill does not offer sufficient protection for staff. Staff should be able to object to being involved for any reason, not only if they have a conscientious objection. People will have different reasons for not wanting to be involved and they should not feel compelled to be involved. We think that the provisions on conscientious objection should be widened slightly, but an opt-in system would be much clearer, as individuals could opt in if they wanted to participate in the process.

Emma Harper: As the convener mentioned, registered nurses are part of multidisciplinary teams. Carers and carers at home can be part of those teams, too. A patient might reach the point at which they wanted to start talking about ending their life. How should we amend the bill in order to protect other members of multidisciplinary teams?

Colin Poolman: It should be made very clear that healthcare professionals should not be compelled to be involved in the process. I mentioned the provision of information and support. I am sure that we will move on to discuss how services could be set up and whether specific services should be provided. That would give individuals access to unbiased information, which would allow them to make an informed choice.

Staff should not feel that they are absolutely required to have such a conversation if they do not feel comfortable doing so or, indeed, they are not trained to do so, but they should know where to point people to. Conversations should take place only with people who have sufficient training, knowledge and understanding to be able to do that. That would have to be part of provision—individuals would need to get specialist training before becoming involved. Again, that comes back to the support that is put into place for everybody involved in the process, regardless of their profession.

Emma Harper: Okay. Would that include pharmacy staff? I saw Fiona McIntyre nodding.

Fiona McIntyre: Yes, absolutely. We believe that it is vital that pharmacists and other healthcare professionals are able to express their right to conscientiously object.

You asked particularly about the description of the process in the bill. Missing from the bill are all the processes that support the safe and effective use of the substance. There is no description of the storage, distribution, dispensing, prescribing and, if necessary, safe disposal of the substance. Our understanding is that, in order for the conscientious objection section to operate, that detail needs to be included in the bill. That would then cover all healthcare professionals who are involved in all those processes surrounding the management of the substance, and the details of that need to be described right the way through the process. We believe that that detail needs to be added to the bill.

Dr Provan: The Royal College of GPs strongly opposes the current drafting of section 18 on conscientious objection. We are very clear that we should not have to justify or approve conscientious objection or not wanting to be involved. There should be wording about it being unlawful to discriminate against anybody who has made a decision not to be involved. Perhaps people could opt in to certain parts of the process, which might allow flexibility. I mentioned an opt-in service model, which eliminates some of those difficulties. GPs are worried about being caught in the middle in the process.

There is potential for moral distress in any clinician who would be involved in assisted dying, because it is a complex and emotional issue. There is a lack of agency in trying to make the best decision for patients, and, ethically, there is a conflict with what they have been taught or brought up with.

Thirty to 50 per cent of clinicians involved from other jurisdictions have an emotional burden or discomfort, and 15 to 20 per cent have an on-going and significant adverse personal impact. We are calling for mental health support for patients, families, doctors and all the team around the decision, as you mentioned.

I emphasise that that is against a background of low morale. Primary care is stressed, with 55 per cent of GPs saying that they are struggling with their workload. We run the risk of losing members of staff if we are not careful about how we implement this if it goes ahead.

Dr Kennedy: The BMA is concerned about the conscientious objection clause. We feel that doctors should have a general right to object to taking part in any aspect of assisted dying. There is a range of views across our profession and even those doctors who are willing to participate in assisted dying are telling us that they also wish to be able to object to taking part if they so choose, because of the distress that they may feel. The activities that doctors who may not support assisted dying may be asked to get involved in include giving an estimate of life expectancy, making a capacity assessment or assuring freedom from coercion. It is therefore important that a general objection to being involved in assisted dying is available to doctors across Scotland.

Brian Whittle (South Scotland) (Con): During our deliberations, there have been concerns about who would be deemed suitably qualified staff, how safeguards would be maintained and how we would avoid someone seeking several doctors' opinions until they got the answer that they were looking for. In the first instance, who should lead and who should be involved in providing assisted dying?

Dr Provan: It is a complex situation. You are trying to think about the patient's capacity to make that decision, which in itself can be complicated and take time to do. You are trying to ensure that there is no coercion, which is also time consuming. To get the best service for the patient, we are in favour of there being a separate service, with those people who have bought in to the service and are used to going through the process with their own protocols. Trying to add it on to a busy general practice would be very difficult, given the subtleties and importance of such situations.

We would like a central source of information, so that patients have independent information. Again, GPs are concerned about being caught in the middle on their decision as to whether a patient would be eligible and whether they have capacity, which clinicians can disagree on. You might need to involve specialists on that issue.

I was very surprised to see in the bill and the notes around it the idea that such a discussion could be added into an extended consultation. The complexity of that cannot be added into an extended consultation. You heard some evidence from Australia, I believe. One of the comments from those witnesses was that such discussions do not work well in busy practices, and there is no such thing in Scotland as a quiet practice. There are even some areas where there are not many GPs, which is why we think that, for the system, the clinicians and everybody involved, especially patients, we need a central service to run this.

Brian Whittle: Where does the RCN sit on the issue?

Colin Poolman: It is clearly indicated in the bill that it would be medical practitioners who would make the assessment. However, as we have alluded to, the multidisciplinary team would assist in that. I share Dr Provan's position on provision of service. This will take time to proceed, if it is done in the right way. These are very complex decisions to have with patients—they are not easy discussions.

At the end of the day, medical practitioners would lead the assessments, but I would imagine that they would be supported very heavily by the rest of the multidisciplinary team that is involved with the patients.

Brian Whittle: Dr Provan and Mr Poolman have alluded to the potential impact on the day-to-day running of our health service, which is under a bit of pressure, as we know. How the proposed bill would impact the running of general medical practice is an added complexity. Dr Provan has suggested that the impact would be detrimental to any GP surgery. Dr Kennedy, will you expand on that?

Dr Kennedy: The BMA does not have an opinion and has not discussed what the service, if it were to start, would look like, but we are absolutely clear that it should be separate and that it would require additional new funding. Assisted dying, if it happens, would be a rare event. It is complex and would require specialist training and guidance. We envisage that only a small number of doctors in the country would be willing to provide the service, undertake training on it and develop their expertise in that area. We see it as a specialised, separate service. It would absolutely not become the standard role of doctors across Scotland.

Brian Whittle: Where does the Royal Pharmaceutical Society fit into the jigsaw?

Fiona McIntyre: I agree with everything that has been said already. The pharmacist’s role goes far beyond just supplying medicine. Pharmacists are within multidisciplinary teams across all care settings. It would be important for patients to receive care from healthcare professionals who are highly trained in the service and that those professionals have the appropriate time to be able to deliver the care and are comfortable taking part.

The Royal Pharmaceutical Society has not discussed how the service would look if the bill were passed, but we are in favour of there being an opt-in situation, whereby a network of healthcare professionals would be able to opt in to deliver the service. Pharmacy services are experiencing similar challenges to other parts of the health service, and it is difficult to see how an assisted dying service could be accommodated within our current provision.

Brian Whittle: You said that the service should be delivered only by highly trained professionals—I would argue that all our healthcare professionals are highly trained. I suppose that it would come down to experience; someone who has just qualified has a different level of experience to someone who has worked in the healthcare profession for 10 or 20 years. From your perspective, Dr Provan, how would we define “highly trained”?

Dr Provan: You can do many forms of training for this. GPs are already skilled in assessing capacity, and part of that relates to coercion. In unique situations such as those that we are discussing, it would be better to have people who are used to doing the work and have the time to do it, especially initially. Doing an online module for six hours does not necessarily equip you or give you the time to have important conversations with patients and ensure that they get the best service. There would have to be protocols for the medications and what to do in certain situations. We would want a central service to hold those medications so that there was consistency, and we would want information to be available in different languages and formats so that patients were well informed.

Colin Poolman: Our healthcare professionals are of course highly trained, but it is about having specialist training to support them, as it would be a completely new process in their practice. They would need initial support and training, as well as continuing professional development. Continued support, such as psychological support, would also need to be provided for those participating in the process. What the service would look like regionally, nationally or whatever is for further debate elsewhere, but, if it were to go forward, you would need to ensure that proper safeguards were in place and that people were properly trained to support individuals.

09:30

The Convener: I have a follow-up question with regard to the bill’s financial memorandum, in which the estimated costs for staff training are £200,000 in year 1, minimal in year 2 and projected to be minimal in year 20. Is that realistic?

Colin Poolman: If that question is directed at me, no, I do not think that that is realistic in the longer term.

A big decision will need to be made in relation to whether you have an opt-in service. With such a service, a specific number of people would opt in, which would be much lower than that for generic training, although, of course, you will have to do generic awareness training for everybody across health and social care. From our point of view, costs will depend on how the service is set up.

We responded to the committee in relation to the financial memorandum to say that we do not believe that those costs are sufficient as currently set out. They would have to be worked through, by considering what the service would look like, the numbers that would be trained and, of course, the detail of the training that would be provided, because that is yet to be decided.

Dr Provan: We, too, think that it is an underestimate for the model that is currently proposed of training everybody in the situation. Again, you could do an online module, but that would not necessarily equip you for the real world, as you would then have to go out and gain experience—GPs have a lot of experience, as I have said, around capacity and coercion, but this is a specific situation. Costs for continuing professional development and learning from and reflection on how the system has worked are not really reflected.

Joe FitzPatrick (Dundee City West) (SNP): I want to ask about coercion—we almost just went to that area. Coercion is one of the big issues that even people who support the bill are concerned about. First, do you think that health professionals have the skills to identify whether coercion is happening? Secondly, is the model that is suggested in the bill the best way forward? Last week, witnesses suggested that a better, alternative system would be to use independent assessors—similar to those the Human Tissue Authority uses to ensure that coercion is not happening in relation to living donors—which would provide stronger safeguards. Is it necessary to have those stronger safeguards, or do you already have the skills in your team? Dr Provan, you almost went to that area.

Dr Provan: GPs know their patients and are skilled in knowing their background, but I do not think that they have the experience to detect coercion in every situation. They do not have the time or headspace to be able to do that in the current model. A centralised model in which independent doctors or a team assess the patient would partly help.

In some situations, coercion will be obvious, and we are trained in adult support and protection, but that is a complex, time-consuming area. Sometimes, coercion is quite subtle—somebody might not feel that they are under coercion but just that they are a financial burden to their family or something like that, which is quite difficult to detect. There are concerns around vulnerable patients in that type of situation, which is why we think that there should be a centralised service, with excellent training and support for a team assessing each patient.

Colin Poolman: It comes down to training and support. People require additional training and support to deal with things such as coercion and bias.

We must also think about the fact that, if the proposal were to proceed, there would be an issue not only about assessment but about what happened when the substance was administered. We have concerns about the fact that the bill does not say that two registered practitioners should be present, because it is a huge responsibility to be placed on one registered practitioner. The bill says that the practitioner "may be accompanied" by another person but, with the stress on services and practitioners, and all the dynamics that would come into play in relation to the process, there might be an issue with that, and we think that some thought should be given to the arrangements around that point in time, so that assessments can be made properly in relation to all the relevant issues, including capacity and coercion, which you specifically asked about. That would put in place another safeguard not only for the patient but, importantly, for the staff.

Joe FitzPatrick: That is helpful. Fiona McIntyre, do you want to respond?

Fiona McIntyre: The Royal Pharmaceutical Society does not have a policy on that aspect of the bill. However, from my perspective, it is important to make the safeguards that will be put in place as strong as possible. Giving professionals the opportunity to opt in to training, which would give them access to all the peer support that would be available in that network, is all about strengthening those safeguards. That provides a way of supporting other professionals who interact with the person and might want to raise a concern, if they feel that there is an issue, and enables them to know who to contact about it.

Dr Kennedy: Doctors already have experience of identifying coercion—for example, in situations in which families might want us to start or stop treatment. However, we feel that coercion is an area that requires specialist training in relation to the provision of any new service. Further, even with training and the development of skills, it is not always possible for doctors to exclude coercion. If it is later established that there was coercion, we would expect doctors to be protected from any criticism.

We understand that, in Australia, there are courses to train doctors about coercion in this context, and we would hope that something similar would be developed in Scotland, should the legislation change.

The Convener: Emma Harper has a supplementary question.

Emma Harper: It seems that 13.47 per cent of GPs responded to the survey that was conducted by the Royal College of General Practitioners. Is that quite a low number? Was it a UK-wide survey?

Dr Provan: It was UK-wide, and that is a reasonable number of responses for that type of survey—as I understand it, that was quite a high response rate, as it is quite difficult to get people to respond. With 47 per cent of respondents being against a change in the law and 40 per cent being for it, I think that it represents the broad range of feelings among GPs on the issue. We are in the process of looking again at our position on assisted dying, and, rather than prejudging that, I am trying to represent the broad view. We want to ensure that, if the proposal goes ahead, patients get a good service and, also, that doctors—our members—are protected. That is the balance that we are trying to get to.

Emma Harper: I acknowledge that 47 per cent of respondents were against the proposal and 40 per cent were for it but, given that legislation is being taken forward in the Isle of Man, Jersey and England, and that people know more about what is happening in Australia, Canada, Oregon, California and other places that have taken forward such legislation, might it be time to conduct another survey?

Dr Provan: I absolutely take your point. When we knew that there were bills going through the various British jurisdictions, we started a process to consider the position of the Royal College of General Practitioners with regard to the practicalities of the issue and the ways in which we support patients and our members. A group, on which some of the views that have been mentioned were reflected, was formed to do that work. It is actively looking at whether to go ahead with a survey and so on, but I cannot prejudge the outcome of that work, which is being done at the moment.

Emma Harper: Thanks.

Sandesh Gulhane (Glasgow) (Con): I declare an interest—I am a practising national health service GP and I chair a working group on assisted dying.

I will follow up on what Emma Harper was asking about. Chris Provan, can you tell me how many people responded to the survey, and what the breakdown for Scotland was?

Dr Provan: I cannot tell you off the top of my head the detail around the breakdown in Scotland, but we can let you know—presumably at a later date—when that information is public and available. We do not have a problem with that.

Sandesh Gulhane: Fantastic; thank you. I ask because the bills are different, and if someone objects to a bill in one jurisdiction, it would not necessarily mean that they would object to another bill in a different one, because bills can be written badly or well.

Dr Provan: I will not comment on that, because it comes back to prejudging discussions that are going on in the college at the moment. Our position is that we oppose a change in the law. We have formed a group to look at the practicalities and to feed back, in order to protect patients and our members, and to consider the best way forward, if this is made legal.

The Convener: Dr Provan, perhaps you could write to the committee with that breakdown of information that Sandesh Gulhane has asked for.

Elena Whitham (Carrick, Cumnock and Doon Valley) (SNP): I remind members of my entry in the register of members' interests: I am a member of the Humanist Society Scotland.

We have already touched on the issue of capacity, but I would like to explore it a wee bit further. Some submissions to the committee set out concerns about the ability of doctors and specialties outwith psychiatry to undertake capacity assessments as part of the assisted dying process. Conversely, last week, we heard from the mental health witnesses that they did not share those concerns, and they argued instead that undertaking capacity assessments was a core part of medical practice. However, they did share a concern that the bill turns an incapacity test into a capacity test, which is different to what they do as part of their work. They were also looking for the reference to mental illness to be removed altogether, and they suggested that more senior doctors be involved in the capacity assessments, as we touched on previously.

Do the witnesses have any concerns about the approach to assessing capacity as set out in the bill, and could you explore a wee bit more what specialist training needs to be undertaken?

Colin Poolman, you are looking at Dr Provan, so we will start with him.

Colin Poolman: Docs generally start.

Dr Provan: Capacity is something that we come across day to day in general practice. We are used to assessing capacity, but it can be complex and difficult, and practitioners can sometimes disagree. Sometimes, we ask specialist psychiatry services to help us to make a decision. We are used to doing those assessments. We have training during our postgraduate years around that specifically, so we know the criteria.

It can be very subtle and time consuming. The position can vary over time, so we have to make multiple assessments, which would be important in such a situation to make sure that a patient still has capacity to make such decisions. Part of the issue comes down to having the time and the headspace to be able to do that with patients. Carrying out home visits and spending a lot of time doing that really important work would take up resources and time.

We also think that it would be useful to have an opt-in system, whereby people are specially trained to hone their skills in this area and have the necessary resources, time and headspace to follow the process through for the patient and do it very well.

Those assessments might not be something that you do frequently as a GP, especially in a rural area, so it would be helpful to have a central service to provide consistency in that regard. GPs are concerned about being caught in the middle a little bit. If they make a decision in favour of one side of a family or a situation, it could be difficult. I think that having a central service would help with that.

Elena Whitham: I will explore that a bit further. If an individual determines that they are not going to proceed with treatment—they are taking a decision that will absolutely result in their death—what is the difference between having a stand-alone consultant or GP assess their capacity to make that decision versus requiring a specialist service to assess someone's capacity to make a decision around assisted dying?

09:45

Dr Provan: The criteria are really the same: people must have the ability to understand and retain information and to make and communicate a judgment.

It can be useful to involve a specialist if there are differences between the family and the patient. That can also be helpful in determining whether someone is suffering from cognitive decline or dementia if they do not already have a diagnosis, because that can clarify the status of the patient and their ability to make decisions. The process can be subtle and it takes time and experience. GPs would certainly want to have the headspace to do that, because it is not something that we take lightly.

Dr Kennedy: I agree with Dr Provan. All doctors assess capacity—consciously or subconsciously—in every consultation. We generally presume capacity, but when we can tell that someone may not have capacity, we will do an assessment.

As I said earlier, the BMA would not regard assisted dying as a conventional treatment; we see it as something different. Assessing capacity can sometimes be ambiguous or something of a grey area and it will clearly need far greater scrutiny in this context. We firmly believe that there should be specific training for any doctor who opts in to providing an assisted dying service.

Elena Whitham: I have a final question, which is about 16-year-olds. Someone spoke earlier about whether 16-year-olds have the capacity to make a decision on assisted dying. However, we allow them to make decisions about healthcare in general. Can you explore that idea? Perhaps Dr Provan could start.

Dr Provan: You would have to make a decision about whether each individual 16-year-old had the capacity to understand, retain and process information. It is difficult to draw a line because it is about the individual's ability to have capacity, so an individual assessment would be needed. That is my view.

Elena Whitham: Does anyone else have any thoughts on that?

Dr Kennedy: The BMA has not considered the difference between 16-year-olds and 18-year-olds.

Paul Sweeney (Glasgow) (Lab): I thank the witnesses for their answers so far and will pick up on some points that were raised during last week's meeting regarding the seniority and specialty of doctors. Are you concerned that the bill is not sufficiently specific about the grade of doctors who would undertake the assessments? Should the bill be amended to define that more clearly?

Dr Provan: The issue is not necessarily about doctors' grades. I go back to the fact that this will be difficult for the average GP practice to undertake and that it will not happen very often. We support having a specialised service staffed by experienced people who will do that more frequently and will therefore be able to assess capacity or coercion in the light of specialised training. We are calling for the bill to create a separate service and have doctors and teams that have bought into having that process, if it is needed.

Paul Sweeney: Might that introduce an inherent bias towards providing assisted dying, as opposed to other options such as palliative care?

Dr Provan: That is a really important point. We emphasise that patients should be given all the options. There is evidence of patients not knowing all the options that are available; we would want them to have all the options in front of them at the beginning. We would like there to be a central service that could provide the initial information and then if the patient wanted to go ahead, their doctor could pass them on to that central service to be assessed on capacity.

Paul Sweeney: Just to be clear, you are saying that you would prefer the bill to specify a service design but that you do not think that it needs to specify qualifying criteria for medical practitioners—is that correct?

Dr Provan: I do not think that a specific qualification is needed, but there would need to be a repository of central training that practitioners could undergo.

Paul Sweeney: Does any other panel member have a view on that?

Dr Kennedy: Mr Sweeney, I think that I saw the evidence that you were referring to—it was from a psychiatrist who indicated that he believed that more senior psychiatrists should be involved. I tend to support that view. The BMA's opinion, of course, is that we believe that there should be a separate, specialised service; therefore, by definition, those doctors would be highly trained in that area. We lean towards the involvement of more senior, highly trained doctors. However, that absolutely needs to be specified. You have identified a gap.

Paul Sweeney: Thank you. Do any other witnesses have views on that?

The Convener: No one else wishes to speak.

Paul Sweeney: I also want to ask about the risk of doctor shopping, which is the colloquial expression. There is a concern that, if someone seeks an assisted death and there is a dispute with clinicians, there may be sufficient scope in the bill for people to seek referrals to a point at which they can get what they want, regardless of the concerns that have been raised by clinicians. There does not seem to be provision for any clinician to raise concerns about safeguarding, for example, in respect of that. Do you share that concern, or do you have a view on whether there should be tighter regulations on the nature of referrals and on who does the referring? If there is a need for a second opinion, should the initial clinician, if they are minded to grant the request for assisted dying, be able to refer onwards to someone who might be in agreement, or should it be more neutral, or more regulated?

Dr Provan: We would have concerns around doctor shopping. As I have said, there can be differences of opinion on capacity, given the subtleties of such situations. I come back to the point that having a separate service that is set up to have the time and resources to do that independent assessment would make things clearer. That would avoid GPs in a practice coming into conflict with the patients, their families or each other.

Paul Sweeney: Is that the idea of having an ethics panel, or some sort of central register, as defined in the bill? Would that be a more satisfactory structure for you?

Dr Provan: To be honest, I had not really thought about those specifics. We are thinking about the infrastructure around which doctors do that function, and who makes the assessment on capacity, coercion and eligibility. That is all that I can say on the situation.

Paul Sweeney: Thank you very much. Are there any final remarks from witnesses, before I conclude?

Dr Kennedy: The BMA would be concerned about doctor shopping. We know that that happens in other aspects of healthcare. For example, people who require occupational medicals will often shop around for a doctor who is more likely to pass them. The phenomenon exists. There should be open and transparent regulation, and there should be an independent body to provide oversight, monitoring and review and therefore reduce the likelihood and risk of doctor shopping.

Paul Sweeney: That is helpful. Thank you.

The Convener: I will move on to the theme of assistance and self-administration. We have heard evidence from other jurisdictions that medical assistance in dying can be administered by physicians, as opposed to there being self-administration. There are different views in that regard. As it stands, the bill provides for the patient to administer the medication. Do the witnesses have any views on that?

Colin Poolman: The bill is clearly about self-administration, so there has to be a clear legal framework to protect patients and safeguard staff who are involved in that process. I go back to the point that I made about the need for two authorised practitioners, not just one, to be involved in the process. That should be explicit in relation to self-administration.

When the assessment is done in relation to the provision that has been proposed, the patient's ability to self-administer should be assessed at that point, too. The bill is not explicit enough about that, so there is an omission in that regard.

Dr Provan: As it stands, the bill is about self-administration. There might be issues with a patient not being able to self-administer because of their condition, as you have heard in other evidence, but extending the bill's provisions to cover a doctor administering medication to end a life would be a step that would alter the whole framework under the bill.

On the practicalities, as I understand it, the bill provides for a doctor to be with the patient after they have self-administered. Doctors are concerned about what their role would be if there were adverse effects in such situations. Should they treat the adverse reaction, because they are not allowed to end a patient's life? That comes back to the protocols and the need to know exactly what the role of the doctor is in such situations. If the provision was not used very often in a rural community, it would perhaps be difficult to go through that process. We want families to be able to cope well with the experience afterwards, so we have to think through exactly how we can allow them to do that without any adverse events.

The Convener: Is the bill sufficiently clear on the types of activities that would be regarded as assistance and would, therefore, be lawful for healthcare professionals to provide?

Colin Poolman: It goes back to what I said about the need for absolute clarity. The bill could be much clearer about what is meant by self-administration, because self-administration can mean lots of different things. For example, if somebody was struggling to swallow and you helped them slightly, that could potentially take you beyond the line. That is why the frameworks need to be laid out explicitly. We do not want to leave any ambiguity, because we know that, in all areas of life, these things are tested when there are disputes. I would hate for us to have gone through a process and for there to be issues for practitioners, who will not just be medics—I think that nurses, predominantly, will be in the position of being authorised practitioners. The bill needs to be much clearer—as clear as it can be—so that there is no ambiguity about what self-administration is.

The Convener: Thank you.

Sandesh Gulhane: I will touch on a couple of topics before I come to my main one. I am a practising GP, and I know that you are, too, Dr Kennedy. When patients who need palliative care have come to you, what has been your experience of that process in general?

Dr Kennedy: All GPs have a lot of experience in that process. Dealing with patients who are about to enter palliative care is common, so it is a core part of our job. Most GPs and patients find it to be a positive process. That is my general comment.

10:00

Sandesh Gulhane: I always find it challenging to convince patients who need it to go to a palliative care service and to have the first meeting about it, because they are scared of the process. Would that form a barrier for some patients?

Dr Kennedy: That is not something that I have experienced or that my members have expressed. However, access to palliative care nurses in the community is a problem. We have far too few and, in my personal experience, it is also very difficult to admit patients to hospices. The provision of palliative care in Scotland is hugely lacking, which is the main concern. The time that GPs and nurses who work in GP practices have to provide palliative care is stretched. My members' number 1 concern about palliative care in Scotland would be resourcing, but they would have no difficulty with discussing the sensitive issues. As I indicated earlier, it is probably the most rewarding part of being a doctor, and the relationship that doctors and patients have built up over many years often puts us in a great position to provide fantastic palliative care with the whole team.

Sandesh Gulhane: A report came out recently showing that palliative care is really struggling financially, among the other issues that it faces. I know that we will discuss palliative care with our next panel of witnesses. Does the bill process give us an opportunity to better fund palliative care, and do you think that that is important?

Dr Provan: It is very important. Patients who are in these situations do not necessarily know about the range of palliative care options that are available. As a GP, I agree that it is one of the most rewarding types of work that we commonly do. It is complex and we need more support for hospices and secondary palliative care, and we need time to have those conversations. In a busy general practice, it is already difficult to have the headspace to have conversations about palliative care, but we try to because it is really important that we prioritise it as an important area of patient care. We have to be careful about how we fund palliative care. I hope that our discussions on the bill will shine a light on that, as well as on what we feel culturally about the end of people's lives and the value of life, so that we get the balance right.

Sandesh Gulhane: We have spoken a lot about palliative care nurses. I agree with Dr Kennedy—in my experience, there are not enough palliative care nurses in our community. More and more people want to die at home, rather than anywhere else. What are your thoughts on palliative care, especially when it comes to our nursing colleagues?

Colin Poolman: I have appeared before the committee many times to talk about our concerns with the provision of nursing in general. Our members who work in palliative care and do an amazing job, as I am sure that we will all agree, have a real concern about people's access to palliative care—specifically palliative care nursing, but all palliative care services. The NHS and the independent providers of our hospices do an incredible job. In my view, they are not properly funded, but that is a different argument. The issue for our members is that palliative care is underfunded. Whatever happens with the development of assisted dying legislation, we should consider how we support our colleagues who offer palliative care and who provide an outstanding service in very challenging times, as we hear day in and day out.

Sandesh Gulhane: Should the bill say that we must talk about the options for palliative care whenever someone requests assisted dying?

Dr Kennedy: My members, who are doctors in Scotland, want to be able to discuss all the options that are available to patients. Doctors do not want to be prohibited from raising any option, including non-treatment options such as assisted dying. As I said, doctors do not want to be compelled to discuss assisted dying, but it should be incumbent on all doctors to discuss all treatment options with patients, as we all do in our day-to-day practice.

Colin Poolman: I am mindful of what that means for individual practitioners. The practitioners I know would generally consider every option that is appropriate for a patient and would discuss those options with them. Once again, protection is important. We must ensure that patients have all the information required to make an informed decision, not only about assisted dying, if the bill is passed, but about all the care that is available to them for the condition they suffer from. That is incumbent on all practitioners anyway, but we might need further safeguards around assisted dying.

Sandesh Gulhane: Fiona McIntyre, I have some specific questions for you about the means of assisted dying. The bill does not specify how that will happen, which I suspect might be because things change in medicine and it might be more appropriate to use secondary legislation. Do you think that that is appropriate, or should the means be specified in the bill?

Fiona McIntyre: The Royal Pharmaceutical Society has not discussed or approved the detail of what that might look like, but any practitioners who are involved in the process or who handle the substance throughout its journey must know what it is. We know from discussions with colleagues in other countries that the substance itself is a closely guarded secret, for obvious reasons. The opt-in framework that we are suggesting would include ensuring that the right people have the right information at the right time, so that they can manage the risk of the substance throughout the pharmaceutical process, as well as when it is being supplied to a patient.

We have not looked at the detail and do not have a firm view on whether that detail should be in the bill. As you say, things can change, as can the availability of medicines, so it might be better to deal with that in regulations through secondary legislation.

Sandesh Gulhane: You have said that the substance is a secret, but we sort of know which medication is used. Do you think that there is a sufficient evidence base for the use of the medication?

Fiona McIntyre: The Royal Pharmaceutical Society has not looked into that in detail, so I am not able to answer that question today. I can follow that up with you afterwards.

Sandesh Gulhane: That would be fantastic.

For obvious reasons, there is no licensed medication for assisted dying in the UK. Do you think that it would be necessary to have that prior to the enactment of the bill, or, given that there is already off-licence use, might that continue to be appropriate?

Fiona McIntyre: The preferred option for the Royal Pharmaceutical Society is for all medicines that are being used to have a marketing authorisation and to be licensed for use, because that safeguards all the healthcare professionals who support the use of that medicine and manages all the risks of that use. We would therefore have a preference for a licensed product.

Sandesh Gulhane: My final question is for all the witnesses, but particularly for Fiona McIntyre.

Is it clear what should happen in the unlikely but possible event of complications during the assisted dying process?

Fiona McIntyre: We have reviewed the bill in detail and think that it is really important to work through all possible scenarios. The role of any professionals in attendance must be clear, and when they might or might not be able to intervene must also be clear. At the moment, there is little in the bill to deal with the risk of an unforeseen circumstance or adverse event. The bill, as drafted, is not clear about whether a healthcare professional would be able to intervene in such circumstances, which might be incredibly distressing.

Dr Provan: I agree with Fiona McIntyre and again emphasise that the role of the practitioner or clinician in that situation must be incredibly clear.

Colin Poolman: We are in agreement with our colleagues.

Dr Kennedy: We at the BMA believe that it is essential for any complications to be recorded. We also believe that there should be a review of every death, which should include the time to the point of death after administration of the substance and a note of any complications. There should definitely be a mechanism for the oversight and monitoring of complications.

The Convener: I thank the witnesses for their evidence. We will suspend briefly to allow for a changeover of witnesses.

10:11

Meeting suspended.

10:21

On resuming—

The Convener: We continue our scrutiny of the Assisted Dying for Terminally Ill Adults (Scotland) Bill with a second panel of witnesses, focusing on potential implications for palliative care. I welcome to the committee Amy Dalrymple, the associate director of policy and public affairs at Marie Curie Scotland; Mark Hazelwood, the chief executive of the Scottish Partnership for Palliative Care; Dr Sarah Mills, lecturer in academic general practice at the University of St Andrews; and Rami Okasha, chief executive officer of Children's Hospices Across Scotland, which is known as CHAS. We will move straight to questions.

Gillian Mackay: Good morning to the witnesses. Can you provide an overview of the current state of palliative care services in Scotland? I will ask Amy Dalrymple to start.

Amy Dalrymple (Marie Curie Scotland): Good morning to the committee and thank you for inviting us. We are really heartened that you are spending some time looking at palliative care, because 90 per cent of people who die in Scotland—that is the intermediate estimate—need palliative care. However, not all of them get it. The best available evidence—although we are currently doing research to update it—is that one in four people miss out on the palliative care that they need. You heard from the previous panel of witnesses about the difficulties that GPs have in securing the right palliative care for their patients.

The palliative care that people get in Scotland is often really, really good, but too many people miss out on getting that care. The recent report from Marie Curie covers England and Wales only, but it reinforces the message that too many people do not get access to the palliative care that they need, which is really relevant to think about in the context of assisted dying, assisted dying as a choice that people make and the context in which they are making that choice.

Specialist palliative care is underresourced. However, it is important for the committee to remember that palliative care is not just taking place in services that are labelled palliative care—it is not just provided by a Marie Curie nurse or a hospice or even a specialist palliative care unit in the national health service. Much palliative care is delivered by GPs, by district nurses, in social care and by non-specialists in hospitals. Palliative care happens throughout our health and social care services, because many of the people who use those services are in the last year of life. It is really important that that context of how people die now be part of what the committee considers when it is thinking about whether, and how, assisted dying might be introduced in Scotland.

Mark Hazelwood (Scottish Partnership for Palliative Care): A lot of good care is being provided by really passionate and committed staff who go the extra mile for people who are facing very difficult circumstances, but it is often provided in spite of a system that does not really assign adequate priority to that phase of life.

Palliative care, in the broadest sense, is a really big part of what our health and social care system does. If you walk into any acute hospital and look around the wards, you will see, on average, one in three people in their last year of life. The majority of people in care homes for older people are in their last 15 months of life, and the biggest single group of people receiving care at home are frail elderly people—again, people with palliative care needs. It is, therefore, a huge part of what the system is about.

Despite that, there is no explicit statutory underpinning for the timely provision of high-quality palliative care. There are no current national standards for it in Scotland, no arrangements for reporting to ministers about its provision and quality and no national programmes of investment for its improvement—indeed, many of the recommendations of the committee's inquiry in 2015 remain unfulfilled. There is insecurity of funding for hospices, which are major providers of specialist palliative care. I am a member of a steering group for the forthcoming new palliative care strategy, and my understanding of the planning assumption is that there is no new money to support implementation of a new strategy.

It is important to think about palliative care in that wider sense. People often think of hospices or specialist provision, which are very important, but palliative care is embedded throughout our care system. We heard from the previous witnesses how fundamental providing palliative care is to general practitioners, and how district nurses and our care homes and care at home services are the backbone of palliative care in the community.

The committee will have heard about what might be described as the frail condition of our health and social care services. It would be fair to say that that frailty applies to much of general palliative care as well, where overstretched teams sometimes struggle to be able to provide the care that they would wish for the people that they are trying to look after.

Dr Sarah Mills (University of St Andrews): I echo that the provision of palliative care is, for the majority of people, very much primary palliative care—care that is being delivered through general practice and district nurses in the community, as opposed to specialist, big-C care delivered in hospices and through specialist palliative care teams. The majority of people who die do not access specialist services but have care provided in the community. That care is very overstretched. Since Covid, there has been a sustained 35 per cent increase in community deaths but there has not been a 35 per cent increase in workforce and capacity in the community. We have absorbed beyond what we can safely absorb to continue to work.

The evidence that we have for palliative care in the community and for primary palliative care is largely pre-Covid, so we are still getting emerging evidence for the impact that Covid has had on that provision. As I said, we are stretched. When everything works—when the planets align and we can provide the services to the patients—palliative care is excellent, but the services are not adequate to meet the need.

Rami Okasha (Children's Hospices Across Scotland): I am from Children's Hospices Across Scotland, and we work with children and young people from the ages of nought to 21. I would say that the position around children's palliative care is a bit different because the population group is much smaller than that for adult palliative care services.

In Scotland, about three children a week die from a life-shortening condition. Most of those children are under the age of five and many of them are babies. Care for young persons and people over the age of 16, which is of course who you are thinking about today, will often be provided by a specialist disease directed team, usually—although not always—operating out of an acute hospital.

We see that the role of palliative care for children and young people takes on some differences from the role of palliative care for adults. Often, it will start much earlier. Palliative care should begin at the point of diagnosis, not at the point of approaching death, and it can often be provided for many, many years. Indeed, in CHAS, increasing medical advances mean that we see lots of young people transitioning into adulthood who, it had been thought, would die in childhood. The patterns of disease that we see are rarer, more complex, and affect a smaller population.

CHAS works right across Scotland. We work in its two children's hospices and we also have teams in every local authority area in Scotland supporting families at home. In partnership with the NHS, we have specialist palliative care teams for children in each of the three children's hospitals in Scotland.

10:30

Gillian Mackay: The variability in palliative care provision and high levels of emergency admissions in the last six months of life highlight the fact that there are very significant gaps in end-of-life care. Does the panel believe that addressing those issues should be a prerequisite for, or a parallel commitment to, the advancement of assisted dying legislation?

This time, I will start at the other end of the line of witnesses and come this way.

Rami Okasha: One of the things that I find concerning is the idea that, for older adults in particular, there is a choice between assisted dying and palliative care. Palliative care should begin early, while active treatment is being provided, and should support a holistic approach to helping people to live well. I would say that palliative care beginning at an earlier stage is a more established approach in relation to children and young people.

I would caution you as parliamentarians not to consider this as people having a choice between palliative care and assisted dying, if that were introduced. The evidence that Amy Dalrymple has led about the need for palliative care across a wide range of people is an indication in relation to that.

There are important questions about access, equity of funding, and ensuring that the appropriate palliative care services are there. Even if this bill were not to proceed and parliamentarians were not to support it, the need for palliative care would remain; and, even if parliamentarians do support it and it becomes law, there would be many people who may wish to access assisted dying, but for whom palliative care would be necessary and would provide significant relief and support for many, many years prior to death.

Dr Mills: I absolutely agree with what Gillian Mackay said in relation to care in the last year of life. We know that, in Scotland, 95 per cent of people who are in their last year of life will have contact with accident and emergency, GP out of hours or the Scottish Ambulance Service. That is not because their needs are being met and they are comfortable; it is because they are having acute needs that are not being met by the care that they have at that moment in time.

If we see that 95 per cent of people in a country have acute unmet needs during their dying phase, then we are not doing enough anticipatory care planning. We are not taking that step back and making sure that people have a plan, have medication in place, and have the security of knowing that, if something goes wrong, there is help for them.

When we can say that we adequately deliver excellent care to everybody who needs it in Scotland, if there were then a small percentage of people who would still, in spite of the fact that their care needs were being met, choose assisted suicide in order to have dignity and a pain-free approach to end of life, then that would be a legitimate choice. However, at the minute, we do not have a legitimate choice, because we have not optimised the care that we are already able to give and that it is legal to give. Until we have done that, changing the law to allow for people to have an assisted death is to give them a false choice.

It would be akin to my saying that my morning commute is terrible because it takes me ages to get there, and so I need a helicopter. In fact, I need buses, or I need the potholes in the road to be fixed; I need the basics to be done and to be gotten right before we have a discussion about whether a helicopter would be a very good choice for me.

We are not getting the basics right for everybody and, until we are doing that, we should not be in the position of considering this.

Mark Hazelwood: I will briefly preface everything else that I have to say by explaining the SPPC’s position, as an organisation.

Assisted dying obviously raises issues of a moral, personal and ethical nature. Those are issues upon which many of our member organisations cannot take a specific position. Our membership includes, for example, all the health boards, all the integration joint boards, a whole range of different charities, the hospices, and professional associations. Therefore, the SPPC does not adopt a position in principle, either in support of or in opposition to a change in the law. However, we aim to critically review and present a view on the specific provisions of the bill, such that, if the bill is passed, the harms—especially to vulnerable people and to the practice and provision of palliative care—are minimised. I say that by way of context.

In our submission to the committee, we raise the idea of contextual safeguards. There is a lot in the bill about procedural safeguards, but people make decisions within a wider context, and that influences the choices that they make. In our submission, we are very clear that good, timely access to high-quality care is an important safeguard.

I echo what colleagues have said. The committee has heard about the deficiencies of palliative care. I talked about those deficiencies in this room when I gave evidence on a previous bill. The one thing that everyone in this debate agrees on is that palliative care needs to be improved. There needs to be more investment in palliative care and it needs to be assigned a greater priority, regardless of the fate of the bill.

As we say in our submission, it is our view that, in considering the future and making choices, it is inevitable that some of the choices that people make will be influenced by their perception of, or the reality of, the care and support that they and their carers might need in order to face the time ahead. We do not think that it is possible to separate out the context. Palliative care is an important part of the context that people are dealing with when they approach the end of life.

Amy Dalrymple: I should make the point that Marie Curie takes a neutral position on assisted dying campaigns; it is neither for nor against the proposed change in the law. We are concerned about equity and about everyone in Scotland—no matter who they are, where they are, what their diagnosis is or how old they are—having the best possible end-of-life experience. All those factors are important because, currently, they all have an impact on how people experience the end of their life.

Last week, we released a report that says that 10,400 people in Scotland are dying in poverty each year. That represents an increase of nearly 2,000 people from the last time that we did that study, in 2019. That will have an impact on how people experience the last years, months, weeks and days of their life. People’s social and economic circumstances will have an impact on that.

There is also the question of the care and support that people can access. Is it really tolerable to any of us that somebody might choose an assisted death because they have not been able to access the palliative care or the social care that they need that would make them comfortable? That question about the context in which people die is one that all of us, whether we are sitting at this side of the table as academics, as campaigners, as people who are trying to develop policy solutions or as practitioners, or whether we are sitting at your side of the table as MSPs, should be trying to answer, because it is hugely important.

The question about assisted dying is whether and how it can or would improve people’s experience of end of life. However, for most people, assisted dying will not be relevant to their experience of the end of their life. Evidence from other countries shows that a really small proportion of people choose an assisted death. For most people who die in Scotland, we are talking about the other factors, which include the equity of access to specialist palliative care and general palliative care. We do not want people’s choice to be dictated to them because they live in a rural area, which means that it is harder for them to access the specialist care that they might need; because they are dying in poverty, which means that their circumstances make it difficult for them to access the specialist palliative care that they need; or because there is trauma in their background, which means that they do not trust the services or find it difficult to access services that might help them to have a better end of life. Such circumstances should not be making people want to choose an assisted death. That is what we ought to be focusing on improving.

Brian Whittle: I will take that theme a bit further and look at the bill's potential impact on palliative care, which we have looked at previously. Although I do not want to, I feel that I have to mention our evidence session with witnesses from Canada, who had diametrically opposed positions—to say that there was a split in opinion would be an understatement. One of the witnesses claimed that palliative care and the resources for it had improved following the legislation, whereas the other witness claimed the complete opposite. One of the things that they talked about was the impact of deprivation on access to palliative care.

Are there concerns about the bill having a detrimental impact on palliative care, or could it have the opposite effect? I will come to Amy Dalrymple first, as she raised the issue in the first place.

Amy Dalrymple: Assisted dying is not palliative care; they are two different things. Regardless of whether the bill is passed, the Government—and we, as a society and as a system—can choose whether to improve and better resource palliative care. If the choice is made not to do so, palliative care will continue to struggle with a lack of resources. We can also decide whether people who are dying should continue to have their care subsidised by charitable donations, whereas care for people who might get better is not subsidised, for example. Those choices can be made, and they do not depend on whether the bill is passed.

Brian Whittle: I go back to the initial question: internationally, in countries that have introduced assisted dying, is there any evidence to suggest, or have you looked at any evidence that suggests, that palliative care has been impacted one way or the other?

Mark Hazelwood: I have looked at some of the evidence, but I am wary of drawing definitive and firm conclusions from international comparisons, because there are very different social, cultural, political, historical and institutional settings in other countries. There is also the problem of different definitions, so trying to compare the data can involve comparing apples with oranges. In many jurisdictions, the record on completion of data in this area is not great, either.

The bill's consultation document included quite a lot of information about resourcing in other countries. I did some comparisons and calculations, adjusting for population, to look at what might be expected to happen in Scotland, given what the consultation document said about funding increases in other countries. It mentioned the Australian state of Victoria, where 72 million Australian dollars was allocated for palliative care. Those were 2020-21 figures, so they are a bit out of date now, but, by my calculations, that would equate to £33 million in Scotland. In Canada, there was a Government commitment to provide 6 billion Canadian dollars over 10 years to improve palliative care, which would equate to £512 million in Scotland over 10 years—about £50 million a year.

10:45

A change to the law to enable assisted dying would not necessitate funding of palliative care. You all know the state of health and social care finances in Scotland, so you might take a view on whether there is likely to be a Government allocation of £512 million to improve palliative care here. I would love it if there were, and we could spend every last penny very well.

The other thing that occurred to me is that we probably do not really need to speculate on what conclusions we could draw from the international evidence, because the real answer lies with the Scottish Government and the Scottish ministers, who might be able to give an indication of what investment might be forthcoming. However, as we have all said before, there needs to be investment in palliative care in Scotland, regardless of what happens with the bill.

Brian Whittle: We are moving along the line of witnesses to Dr Mills; we keep on adding layers.

Dr Mills: I echo and support everything that has been said. Palliative care is separate to assisted dying and should be funded and resourced, whatever decision is taken on the bill.

On your question about international evidence, I am familiar with the Canadian system—I was born in Canada and came over here when I was 20. My understanding, which would apparently agree with that of half of your experts, is that funding for palliative care has gone down since the introduction of assisted dying.

Funding is fickle and flows with political will. Whenever there is an alternative to any medical specialty, it follows that there might be a reduction in funding for research and investment in that specialty. If assisted dying is seen as an alternative to palliative care, as opposed to a separate decision stream, there is a risk that investment in research in and clinical delivery of palliative care would be affected.

Brian Whittle: Lastly, Rami Okasha, what would be the impact for the cohort of people who you look after?

Rami Okasha: The international evidence is contested, as you have heard. What I would say to you as parliamentarians, though, is that you should consider the bill that is in front of you. The scrutiny that you apply and the decisions that you make should be based on the contents of the bill rather than on what might happen in other jurisdictions or on where you think funding might flow.

There is a very strong case for increasing investment in palliative care—it has a relieving effect on other parts of the healthcare system, so there is an economic case for doing so. There is also a moral case for investing in palliative care.

In CHAS, like other organisations, we have not taken a moral position for or against assisted dying, but we have significant concerns about the detail of the bill that is in front of the committee. I would encourage you to make sure that your deliberation and scrutiny are focused on the content of the bill rather than on any issues around funding.

Elena Whitham: I will cover the theme of assisted dying as an adjunct to palliative care. We have heard quite clearly that we have to look at assisted dying and palliative care as two separate things, and I think that that is absolutely right. We have had written submissions and oral evidence saying that palliative care can be complemented by assisted dying as an alternative. People have stressed that there is a therapeutic value to having a choice of an assisted death and how that can remove an element of suffering not addressed by palliative care, even if it is ultimately not exercised.

Conversely, we have also heard that the two are not compatible and that assisted dying would divert resources away from palliative care and erode its quality and availability.

I would like to explore that a little bit. Do witnesses recognise the potential therapeutic value that accessing assisted dying can have for individuals approaching the end of their life, especially those individuals for whom the best palliative care would perhaps not be enough to relieve their suffering?

I will start with Amy Dalrymple and work across from left to right.

Amy Dalrymple: That is not something that Marie Curie has researched or has taken a position on. Palliative care can be done better. However, even if it was provided to its full potential for everyone and we had as perfect a palliative care system as we could get, I would not want to overclaim and say that every individual would have what you might call a good death. However, it would be a very small minority of people for whom that would not be adequate. If that is the rationale behind supporting assisted dying, it should be recognised that it is for a very small minority of people. I cannot comment on the specifics of your question, because we have not done the work to support any position on that.

Mark Hazelwood: In our submission, we described the quite common experience of specialist practitioners in palliative care of having somebody, who has perhaps just received a diagnosis or bad news about the worsening of their condition, express a wish to shorten their life. It is not uncommon, certainly in specialist palliative care, and I am sure more widely.

A big part of palliative care is to surface, to explore and to seek to understand the causes of those feelings, because many different causes or feelings might lead to a person expressing that view. People are often scared about the end of life—they might have heard things that have led them to be very alarmed about what could happen towards the end of their life. They might have practical concerns about their finances and their loved ones, and they might feel that they will not get the support that they require. As you can imagine, a huge amount is going on inside people’s heads in those profoundly difficult circumstances.

At the moment, our system’s response to that expression of suffering is to seek to understand and address the causes of suffering. One of the reasons why many practitioners of palliative care have some concerns about the bill is the very common experience of somebody expressing to them a desire to shorten their lives but, following discussions to understand the causes of that suffering and the measures to address it, then changing that view and going on to live a good quality of life for extended periods, in the context of their living with an incurable condition that will lead to the end of their life. You can imagine the importance that practitioners assign to listening to that expression of suffering, and perhaps this desire to shorten life, and getting into conversations about what underlies that. That is a major cause of the concerns that many practitioners have around the bill, whether they have a definitive position for or against it.

I will add that some people do have an enduring wish to hasten their death, and there is a need and a right for that wish to be respected, affirmed and valued. That applies regardless of what the law does or does not enable.

That is quite a long answer. There is a big therapeutic value in unpacking the causes of people’s suffering that might lead them to express a wish to hasten their death. Not all suffering can be ameliorated even with the very best palliative care, which not everyone gets access to.

Elena Whitham: I am actually going to ask you whether you can lengthen your answer a little bit for me. I want to explore the therapeutic effect that access to assisted dying has reportedly had for some people who may not eventually exercise their right to it but who report that unpacking those really difficult conversations with palliative care specialists—availing themselves of that opportunity to explore all the options—allows them to live as best they can for the remaining time, even though they do not exercise that right at the end.

Mark Hazelwood: I think that there are two different things going on there. If you are talking about a palliative care intervention, that is distinct from having support to end one's life, which is obviously what the assisted dying bill proposes.

Assisted dying is not part of palliative care. The World Health Organization definition of palliative care is very explicit that palliative care does not involve the hastening of death. With regard to the impacts on palliative care, one issue about the bill and the debate surrounding the bill is that there is quite a lot of confusion about what the term "assisted dying" means. There is polling evidence that the public believe that assisted dying encompasses things such as the right to refuse treatment that they do not want or the withdrawal of life-sustaining treatment, and that a smaller percentage of people believe that it even encompasses things such as hospice care.

In our submission in response to the bill proposal, we presented a case that more explicit language should be used to describe the bill, because the term "assisted dying" is not well understood and, in a plain English sense, could be felt to describe all sorts of things that are already palliative care practice. That is more than just some esoteric point about language because, for a practitioner who is engaged in having conversations with somebody in these circumstances, those conversations are already complex and nuanced. One impact of the bill is that we need to try and make sure that people are talking about the same thing at the same time. That will add another challenge to what are already complicated and tricky conversations to have.

I do not know whether I have answered your point there.

Elena Whitham: That is quite helpful. The questions that I am trying to get at are in relation to assisted dying being an adjunct to palliative care. They are two separate systems, but if the bill became law, there might be an integrated pathway where the two systems would have to interact with each other—it is about considering how they could mutually benefit the patient.

In the interests of time, I will move on and let Dr Mills and perhaps Rami Okasha answer as well.

Dr Mills: It is a complicated situation. I put in my written submission that I am against the bill. That is my position on the bill, but it is not necessarily my position on assisted dying, which is a very complicated and nuanced issue that needs to be explored in greater detail.

On whether there are therapeutic benefits for patients in knowing that they could end their lives at a time of their choosing, as I understand it, there is no research to support that. That is not to say that it does not exist, but I am not aware of research supporting that. It is certainly something that should be looked at if the bill becomes legislation.

I certainly think that there is therapeutic benefit in being able to say to patients that you will relieve their suffering or for them to know what the plan is and that there is a plan that will relieve suffering and distress that is acceptable to them. They need a plan so that they know what to do if things are going wrong and they know who to call or who their family can call if things go very wrong. The current state of palliative care is that not everybody has that in place.

We heard from Amy Dalrymple that one in four people who could benefit from palliative care are missing out on it. We know, through my research and the research of others, that 20 per cent of patients do not access even emergency or unscheduled care services at times when they could benefit from such services. We know that, in other areas in the UK that have gold-standard palliative care services that are opt-in services as an adjunct to primary palliative care, only about 50 per cent of the patients who die there access those services. We are seeing that there is a huge gap in how care is being delivered.

11:00

A lot of the distress around dying comes from people not knowing what to do when things go wrong, what is going to happen and whether they will be comfortable. We can alleviate a lot of the fear and anxiety around death with good-quality palliative care, but we are currently not able to do that for everybody who needs it.

One of my serious concerns is that the bill has been introduced during the current crisis in both health and social care. A lot of the distress may be about whether people will have carers, whether those carers will be people that they know and whether they will be able to have care at home. Where practices have access to community hospitals or palliative care beds, a lot of patients certainly find relief in the knowledge that they can have that level of service or that level of input should they require it. Relieving suffering in that way is a huge priority and we need to do more of it.

Rami Okasha: Society fears death, and we do not talk about death enough. I think that most children and young people who die, including young adults, are supported to do so peacefully, with dignity and with much love and compassion. However, thinking about both children and adults, I say to you that no regime, whether it includes assisted dying or not, can eliminate all suffering, and it would be wrong to think otherwise.

The question for you as parliamentarians is where the balance of risk should lie based on what you see in society and what you see in the bill. On Dr Mills's point, it is perfectly plausible for someone to say that they are in favour of assisted dying but that they find flaws in the bill. Some of the things in the bill certainly require much more attention.

In relation to the efficacy of children's palliative care, it is well documented in the literature that there are symptom-management approaches that are very effective at relieving even the most complex pain. However, there is a need for more research into symptom management, particularly in relation to rare conditions.

I encourage you as parliamentarians to focus on the specifics of the bill, which covers a number of areas and includes a very broad and, I would argue, flawed definition that would encompass many more people than you might expect. I encourage you to think not just in the abstract, but about the specifics of the bill that you are scrutinising.

Emma Harper: Before I come to my question about conscientious objection, I ask Rami Okasha what he meant when he said that there is a definition in the bill that would open it up more widely. Is that the definition of terminal illness?

Rami Okasha: Absolutely. The proposed definition is imprecise, and it is so important to have clarity in the bill. There is no consensual understanding of the terms "advanced" and "progressive". There is no agreed definition of what those things mean.

I will give you an example. A young person may have an advanced and progressive condition that will inevitably mean that their life will be short, but they will live into adulthood and have a number of years left to live. That condition would fall within the definition in the bill. I can think of a number of progressive conditions that can present as being, arguably, "advanced" at a stage that will be many years before death. I encourage you to apply more scrutiny to the definition in the bill.

Dr Mills: It also fails to account for multimorbidity. We know that, by 2040, about 40 per cent of the people who are dying will be dying from multimorbidity conditions as opposed to a single disease that is causing death. The bill mentions "an advanced ... condition", but it does not say what will happen for a 90-year-old lady who has failing kidneys, a little bit of heart failure and a little bit of respiratory failure and has a fall as well. We see a lot of complexity around end-of-life care that is not reflected in the definition.

Rami Okasha: I was going to say a few other things, but I can see that other hands are up.

The Convener: Please cover your points—briefly, as we still have a lot to get through.

Rami Okasha: I will be happy to do so.

Another concern of mine about the definition is on the assessment of young people and children who are transitioning into early adulthood. The conditions that they present with are often rare and complex—they are not often seen in primary practice, and the person will be under the treatment of a consultant in a hospital. Much more consideration is therefore required of the level of expertise that is involved in making such judgments.

Emma Harper: Okay. I will go on to my theme of conscientious objection.

The Convener: Yes, if you do not mind. I ask that we keep questions concise and to the point—and if panel members can do similarly, I will be very grateful.

Emma Harper: Okay—thanks, convener.

I have been a nurse for more than 30 years. I am interested in issues of conscientious objection. Is there enough clarity as to which staff and activities are covered by the conscientious objection provision in the bill?

Rami Okasha: In short, the answer is no. The detail is not sufficient. I found the evidence that you heard from Mary Neal on that point to be very compelling. I am very pleased that there is a policy intent to allow conscientious objection, but the wording in the bill is not sufficient to deliver the intent that is set out in the policy memorandum.

Emma Harper: Would you prefer further provisions in the bill to protect professionals if the bill progresses and becomes an act?

Rami Okasha: Yes, absolutely. At the moment, the words in the bill do not give rise to the policy intent to give certainty about conscientious objection.

Mark Hazelwood: There is not sufficient clarity in the bill on the scope of conscientious objection. In your session last week, you heard a concern that the bill can be passed without any meaningful conscientious objection provision, because of reserved powers issues.

For our organisation, there may be reasons for objection that are other than conscientious. We have said that professionals need to have the ability not to participate, regardless of whether that is grounded in a conscientious objection.

Lastly, the conscientious objection that is in the Abortion Act 1967—on which, to an extent, the bill draws, I think—is quite narrowly drawn. We wish to see flexibility in the bill such that people who may be peripherally involved in the process of assisted dying would also have the ability not to participate. I am thinking of something that we will probably come on to, but I will stop there, because you asked us to be brief, convener.

The Convener: I used the word “concise”.

Dr Mills: I agree that there is insufficient clarity on conscientious objection. Throughout, the bill lacks the clarity that would allow us to be very clear about how the service is to be delivered. The conscientious objection provision needs to follow from that. For example, if the service is to be delivered through general practices, what happens if a single-handed GP in Orkney has a conscientious objection? Who takes care of their patients? There needs to be a lot more specificity throughout the bill in order for the conscientious objection to have meaning and for there to be a legitimate back-up plan for patients whose only medical contact may be someone who conscientiously—or non-conscientiously—objects.

Carol Mochan: We have heard from different countries that have taken part in our evidence that there are different approaches to doctors’ responsibility to discuss assisted dying with their patients.

A number of people who have responded to the consultation, particularly those who are interested in the law, have asked whether there would be a duty for doctors to raise assisted dying with patients as a treatment option if the bill was passed. I am interested in your views on that in the bill as drafted, and the implications for doctors and staff.

Amy Dalrymple: My reading of the bill as it stands is that it does not indicate whether anybody would be obligated to discuss assisted dying with a patient, either proactively or reactively. I do not think that there is anything in the bill about that at the moment. Were an obligation or a lack of one to be introduced in the bill and if that clarity was to be provided, bearing in mind the Montgomery v Lanarkshire health board ruling in Scotland, we are of the view that other treatment options ought to be discussed as well.

That leads clearly to the point that we were discussing earlier about the adequacy of the provision of palliative care, as well as social care, being relevant to people who would be eligible for an assisted death and any other forms of care and support. It would be wrong to raise and discuss palliative care and social care as options for care and treatment if they were not actually available, but assisted dying was available. You have to ensure that the treatment options that you are discussing with people are available. The choice ought to be genuine and not one that has been driven by circumstances that have been dictated by a lack of resource.

I hope that that is helpful.

Carol Mochan: Does anyone else have a view?

Mark Hazelwood: The bill is silent on the matter. We have raised a concern that the Montgomery case may constitute a common law duty for doctors to raise the topic of assisted dying with patients. In our submission, we have raised some of the potential difficulties and complications around that. If a doctor raises assisted dying proactively, that has the potential to shut down the exploration of other issues and problems. It has the potential to send very negative messages to the patient that their life is not valued, that other measures might have been deemed to be inadequate, and that there is not hope.

From extensive research, we know that how people with advanced illness feel about themselves is quite strongly impacted by the way in which they feel that they are viewed by health and social care professionals. It is in that context that we raise that concern: what message would it send to a person who is in a very vulnerable situation if it is perceived that someone has suggested that assisted dying is an option for them?

Dr Mills: It is an important point to consider. It is very difficult to make it a requirement for doctors to raise assisted dying with patients. As I have said, the identification of people who are in the last year of their life is imprecise and suboptimal as it is. You could be in a position in which you have introduced a requirement for a doctor to discuss assisted dying with a patient who they may not have realised is dying, or when the patient has not realised that they are dying. The doctor may be in a position in which they are discussing matters with family members when the patient is very much at the end of life, and family members say, “Why didn’t you bring up assisted dying before they were in their very last days and weeks?”

We know from a number of pieces of research that the average identification of death is very much in the last months, if not the last weeks, of life, rather than significantly before that. The timescales as set out in the bill seem to assume that we all know who is dying and the timeline that they will have, and that it is a very predictable thing that we can take a large step back from. The identification of people who would be expected to be within their last year of life is hugely complicated and nuanced, and is the subject of on-going research in a number of places.

11:15

There is also the fact that a doctor cannot raise something in a medical consultation in a way that is neutral. If a doctor says to someone, “Have you thought of quitting smoking?”, that is not a neutral question. With most of what we bring up in a consultation, patients take it to mean that we are in favour of it, whether or not we try to present it in a neutral way.

If we were to envision a future in which there was assisted dying provision running parallel to the provision of palliative care, it would be similar to what we see now with NHS and private work. If I say to a patient who is awaiting knee surgery, “Have you thought of going privately?”, I am saying to them, “I don’t think the NHS can provide the care you need on the timeline that you need it, and I think you should explore your other options.” Saying to a patient who has a terminal illness, “Have you thought about assisted dying?” would have that same subtext, and I think that that would be very challenging.

Given the difficulty in identifying patients who may be dying and the weighted nature of bringing up the issue of assisted dying in a consultation, it is not possible to tell doctors that they have a duty to do so.

Rami Okasha: In relation to children and young people, I cannot envisage a circumstance in which it would be ethical to raise the issue proactively with a family or a young person. I say that for three reasons. The first is the very privileged relationship that healthcare professionals have with children and young people and their families; they may have known the young person for a considerable period of time prior to the age of 16.

Secondly, there are the broader issues around the appropriateness of the age threshold—we may come on to those. The third reason is the difficulty of prognosis in relation to disease that presents in young people. It is often extremely difficult to understand what a prognosis may look like where an individual clinician is dealing with a very rare condition that they may not have previously seen in Scotland.

The committee would need to reflect on that area very carefully.

Dr Mills: Given the current state of the NHS, a lot of wait lists for secondary care are now more than a year long. In primary care, we are frequently in a position where we see someone who is clearly dying, but who does not yet have a diagnosis for the condition that they are dying from.

Primary care practitioners may be in a position, because of the state of the NHS, where they do not have a diagnosis for a patient whom they have referred to secondary care. It is unfair to require a GP to have a discussion with an as-yet-undiagnosed patient about assisted dying from a condition that has yet to be diagnosed. I think that that circumstance would not be unique in the way that one might hope that it would be.

Carol Mochan: Thank you—that answers my questions.

Paul Sweeney: I thank the witnesses for their contributions so far. I want to ask about the definition of “terminal illness”. Section 2 of the bill defines someone as terminally ill

> “if they have an advanced and progressive disease, illness or condition from which they are unable to recover and that can reasonably be expected to cause their premature death.”

A number of concerns have been raised by stakeholders about the breadth of the definition and the potential for it to include a wide range of long-term conditions. Some have proposed that the inclusion of a prognostic timescale, such as the timeline of six months in the UK Terminally Ill Adults (End of Life) Bill, or a wider definition of 12 months, would be an effective means of narrowing the definition.

On the other hand, others have raised concerns that the definition is too narrow and could discriminate against people who are experiencing other non-terminal conditions that nonetheless bring unbearable suffering.

From a clinical perspective, what types of conditions do you think would be covered by the definition of terminal illness in section 2 as currently drafted? What would not be covered? If anyone has any initial desire to respond, please do so.

Mark Hazelwood: I am not a clinical person—there is a clinician on the panel who will be able to give you a more technical view on that. Nevertheless, the key terms “advanced and progressive” disease and “premature” mortality are not precise and do not have agreed definitions, so the definition in the bill does not deliver the clearly defined and quite narrow cohort that seems to be the policy intent as set out in the policy memorandum. That will result in variation in interpretation, with the public and practitioners being confused about who might be eligible, and there will be inconsistency. That is a real concern about the bill.

Section 23 gives ministers the power to make guidance and section 23(2)(a) refers to guidance on assessing eligibility. When you move from the quite brief definition in the bill to thinking about practical assessment and implementation, you will come up against the complexities and difficulties in trying to create something that is coherent and is tidy round the edges, which will be very difficult.

I have some personal experience of that. When Social Security Scotland was being established, I was asked by the office of the chief medical officer to chair a group that was trying to put together guidance to support the brief legal definition of terminal illness that was in the Social Security (Scotland) Bill. We found that it was very difficult to take vague terms such as “advanced and progressive” disease or “premature” mortality and to apply them precisely in practice. We were keen to broaden eligibility and to provide fast-track access to terminal illness benefits for people who were approaching the end of life.

Whatever the bill says about the scope of those who would be eligible for assisted dying, that could vary quite a lot, depending on the assessment that the Scottish ministers develop. That creates the potential for the definition to be vulnerable to scope creep, because any definition that is not clear is inherently contestable.

Paul Sweeney: Do you have a preference for how section 2 could be amended?

Mark Hazelwood: I do not have a clear and simple conclusion. I know that the bills that are being discussed south of the border—and perhaps also bills that were previously discussed in this Parliament—include a prognostic timeframe, but that is problematic. I expect that you have already heard evidence about the difficulties for clinicians in providing a clear prognosis with any degree of confidence.

We do not have a view on whether that would be better or worse than what is in the bill, because we are commenting on the provisions of the bill that is before us, but I know that there are real difficulties in providing that sort of prognostic accuracy.

Dr Mills: The definition is very vague. Does premature mortality mean dying before the average age of death for the population, so that anyone dying after the age of 74 would not be considered to be dying prematurely and therefore would not come within the scope of the bill? The bill also fails to consider multimorbidity as an increasingly common cause of death. People are dying because of more than one condition rather than because of a single condition.

I agree that it is tempting to put in place a timeframe, because that would narrow the definition. As things stand, quite a lot of my patients who are living very well with advanced diabetes, or other advanced conditions that could reasonably be seen to hasten their death, would fit the definition.

The definition also does not cover patients who suffer a single catastrophic incident, such as a stroke or being hit by a bus, because that is not “progressive”—it is not expected to necessarily happen again. The definition itself, therefore, needs to be looked at, and that is beyond the expertise that you have in the room or that you have heard from.

A doctor’s ability to decide whether somebody is in their last six months or year of life is very imprecise. Determining whether somebody is in the last year of life—my research focus is on that last year—is hugely challenging and incredibly complicated. I was smiling earlier, because I am on call for Christmas eve this year, and the patient who I told would not have another Christmas has said that he will phone me at five minutes to six to tell me that I was wrong.

Paul Sweeney: You have clearly highlighted the challenges with prognostic forecasting, given the complexity of life, really. To build on your point about a catastrophic neurological event, are there specific conditions that you think should be more clearly defined in the bill or, indeed, things that should be specifically excluded, such as diabetes, for example?

Dr Mills: Given the scope of expertise and the experience that is available in the room, you cannot ask us to pin down a definition that will work for the bill. One of the huge risks in this area is providing a definition that encompasses everyone instead of working for the people for whom assisted dying might well be the preferable choice. In my 15-year career, I have come across perhaps three people for whom I felt that assisted dying was absolutely the right thing and nothing else could be done medically. However, I see three people a day who would fit the bill’s definition.

The legislation should allow for that very small number of people for whom even the best palliative care cannot adequately control their symptoms to access assisted dying. It should not raise the question of assisted dying for the vulnerable, the elderly, people from protected and minoritised backgrounds and people from inclusion health groups, who would feel huge amounts of psychological and social pressure to proceed with assisted dying for financial reasons, for example. Whether there is direct coercion by other people, people at the end of life very keenly feel the pressures of not contributing economically and, perhaps, of needing extended levels of care and the impact of that on family and friends. The definition as written does nothing to protect those vulnerable people.

Paul Sweeney: What is your view on including a prognostic timescale? Would you be content to include in the definition something equivalent to the timescale in the UK bill that I mentioned, which is six months?

Dr Mills: It would be ideal if we lived in a world where doctors were able to say definitively what somebody's prognosis was—that would be bewitchingly simple and we could dispense with a lot of the discussions on this issue—but that is not true, frankly. Any doctor who feels that they are able to adequately predict somebody's prognosis in months and years is usually mistaken. I have seen three people this week who I thought were going to be dead but are not. It is very imprecise. Until we improve on the precision and accuracy with which we can identify somebody's prognosis, it is meaningless to include a timescale in the bill, because you will find that, with 10 doctors in a room, you will get 10 different opinions.

Paul Sweeney: Does Mr Hazelwood's point about section 23, which gives power to the Scottish ministers to define guidance or even provide specific regulation on what the qualifying criteria might be, give you some comfort that it could be an evolving situation, and that a better definition could come through secondary legislation?

Dr Mills: The primary legislation should have an agreed and acceptable definition. We should not pass it in principle and then try to fix it in secondary legislation.

Paul Sweeney: Do Mr Okasha and Ms Dalrymple have any views on the definition of "terminal"?

Rami Okasha: I, too, am not a clinician, but I can reflect the views of those clinicians who I work with, who are very skilled in that area. When it comes to young people, prognosis is even harder. Many of those conditions are rare; they are not often seen. The course of illness is unpredictable and the rate of medical advance is really astounding.

11:30

I give the example of Duchenne muscular dystrophy. Ten or 15 years ago, CHAS would have supported many young men—it is usually men—with DMD, because they would be expected to die in their teens or perhaps very early twenties. The rate of medical advance now is such that we support very few people in those circumstances, because longevity has improved to such a point that people who have that diagnosis are living into their thirties and, in some cases, beyond. The rate of advance is significant.

I take a different view on the point that you make about the flexibility that is afforded in the bill and the enabling powers for ministers. They are concerning and would allow changes and expansion to the definition without the type of parliamentary scrutiny that you are providing today. The definition is fundamental to the bill. If you cannot describe in the bill the population that is encompassed, that is problematic. More work is needed in that area.

Paul Sweeney: What amendments to the definition might satisfy you?

Rami Okasha: That is a very difficult question to answer, and I do not have a simple amendment, because the issue is not simple. It is complex, and it goes to risk, ethics and some fundamental decisions that you and other MSPs will need to take on behalf of society about what level of risk will be acceptable in a regime that allows us to die.

Paul Sweeney: Ms Dalrymple, do you have any comments on that issue?

Amy Dalrymple: I have two brief comments. I again make it clear that I do not have any clinical training. The definition as was, to add to the point that Mark Hazelwood made earlier, was developed as part of a campaign by Marie Curie, among others, as a broad and inclusive definition that deliberately did not include prognosis in order to enable people to have access to the financial support that they need when they get a serious illness without requiring a prognosis agreed by a doctor to say that they were in the last six months of life. That confirmation, through the DS1500 form, was previously a requirement by the Department for Work and Pensions. That does not mean that that is an appropriate definition for any other legislation that is about people with terminal illness or who are at the end of life; it was very deliberate.

My other point is to reinforce something that Sarah Mills said. The fastest rising cohort of people dying in Scotland and across the UK are those over 85 who would not have a diagnosis of any terminal illness but might, for example, have a bit of kidney failure, be very frail, be in pain or have a wee bit of cognitive decline. My reading, and our reading at Marie Curie, is that the definition in the bill would exclude that group.

The answer to your question could be that the definition is both too broad and too narrow, and that it perhaps needs to be looked at again. That is a question for you, but you might want to decide who you want included and who you want excluded first, and make sure that you are drawing a definition around that, rather than necessarily using something that was developed for another piece of legislation with a very different intent.

Paul Sweeney: Just finally—

The Convener: Mr Sweeney, if your question is very brief, I will let you ask it.

Paul Sweeney: Of course, convener. My question is about the European convention on human rights. Regardless of what the bill defines as a terminal illness, there might be scope for the courts to extend that in future. Does anyone have concerns about that?

Rami Okasha: That has certainly happened in other jurisdictions. It comes back to the necessity of having a definition that delivers the policy intent that you as parliamentarians wish, but, at the moment, that is not there.

Dr Mills: I absolutely agree. If the bill is passed with the wording as vague as it is, it is inevitable that that would happen.

Mark Hazelwood: To echo others, the definition is imprecise, and I think that that leaves it vulnerable to legal challenge or interpretation. We have raised that concern in our submission.

The Convener: We have touched on the age of eligibility. The simple question is, is 16 an appropriate minimum age to make a decision on assisted dying?

Rami Okasha: Our view on that is no, and that insufficient consideration has been given to the appropriate age. The rationale for the age of 16 is unclear and having that minimum age would make Scotland an outlier in relation to legislation of this type, which is about terminal illness, as opposed to some of the international comparisons, which are based on unbearable suffering. It would be an untested area.

There are many precedents in Scottish public policy for having a higher threshold for adulthood, on grounds of vulnerability. You have to be 18 to serve on a jury or buy alcohol, and special considerations are put in place around young adults who wish to donate an organ to the Scottish transplant programme, for reasons of vulnerability.

The laudable legislation that the Parliament passed on the United Nations Convention on the Rights of the Child recognises that adulthood begins at the age of 18. In Scotland, there is a recognition in the child protection legislation that there are nuanced decisions to be made in relation to the ages between 16 and 18, and I would say that this is an area in which caution is needed. For example, one of the reasons why, in the Scottish courts, sentencing decisions are different for people up to the age of 25 is that there is a recognition that the brain develops over a period of time and that it does not switch to being an adult brain at any one particular age. We know that the sentencing guidelines consider young people to be less able to exercise good judgment in relation to really complex decisions, and that there is an acknowledgment that younger adults, particularly those around the ages of 16 to 18, are more susceptible to negative influences, more likely to go into difficult relationships and less likely to think about risk.

Parliamentarians have set different age ranges across various policy areas, and you must be wary of taking an easy approach that says that, because the minimum age for one thing is a certain age, it should be the same for another thing. You need to think about the facts of the issue that we are discussing and come to a position that reflects the gravity of the decision and the risks that are involved.

The Convener: Does anyone want to add to Rami Okasha's answer? It was extremely comprehensive, and answered the two questions that I was going to ask next.

Dr Mills: If you are looking for a research base to underpin your decision, I would say, from an academic perspective, that the majority of papers that are written on this area would exclude people under the age of 18 and would focus on adults only.

Mark Hazelwood: The SPPC concurs with and supports the view that Rami Okasha has expressed.

Amy Dalrymple: Marie Curie is an adult provider, so we must take a neutral position on the question. In Scotland, we are not the experts on children and young people's palliative care; CHAS is.

David Torrance (Kirkcaldy) (SNP): In the evidence session that we had with witnesses from Canada, we heard of cases in which people's family members or loved ones had opposed the process for assisted dying. Should family members and loved ones be involved in the decision-making process for assisted dying?

Amy Dalrymple: Are you asking whether they would have to consent to a family member having an assisted death and would, for instance, be able to raise an objection that would have an impact on whether the person could have an assisted death?

David Torrance: Yes.

Amy Dalrymple: That is a very interesting idea. My colleagues who deliver palliative care quite regularly deal with family conflict over decisions that are made in palliative care provision. Perhaps Sarah Mills can talk more to this, but an example would be finding a balance between sedation to manage a person's pain symptoms and their desire to maintain an ability to socialise with friends and family, as that is the person's view of the quality of life that they want. You have to make a decision, but in making it you have to prioritise what is most important to that person. You always prioritise the wishes of the person, not their family members.

Family members and carers have an important contribution to make to a person's care, but we are talking about adults who have capacity—depending on how that is defined, and I know that there are big questions around that. However, basically, it is that adult who would make their own decision. You raise an interesting question, which is whether assisted dying is a medical treatment, given that family members would not have that role for other medical treatments.

David Torrance: Does anybody else have a comment?

Mark Hazelwood: I do not think that there is any mention of family in the bill, so that role is not something that the bill addresses. Not everyone has a family, of course, or even a range of social networks.

It is a tricky area, as Amy Dalrymple said. Palliative care encompasses the care of people around the person who is approaching the end of life and it is not clear what applies here. I can envisage there being a range of circumstances where a balance must be sought between the need for patient confidentiality and autonomy, and what might be very complex, contested and conflicted views among the surrounding social network.

There is another element of family involvement in assisted dying—I do not know whether we will come on to this, and it is not the intent of your question—and that is around understanding the circumstances in which somebody may be coerced. That is probably not what you are thinking of.

David Torrance: No.

Dr Mills: If assisted dying is a medical treatment for an adult who has capacity to consent for themselves, we would not necessarily take the family's views into consideration. As part of providing palliative care, we frequently have discussions with patients and families. Consented decisions are often made and they often form the basis for anticipatory and future care planning, and we keep those as records. However, certainly, if somebody had capacity and the family were objecting, I would expect that, in Scotland, a consenting adult with capacity would have the right to consent to a medical treatment, irrespective of their family's views.

My main concern about the role of family would very much be about coercion and the role that the family was playing that the medical practitioner might not be aware of.

Rami Okasha: For young people and young adults, their family is often, although not always, their primary carer, so the relationships are a little different. My concern is less about coercion and more about the feeling of being a burden. I have heard people talking about the risk of being a burden on their family. That is a worry and I hope that that would not be a consideration in a decision.

In that regard, however, one of the challenges in the detail of the bill is the capacity assessments that we look at. Those would allow someone who meets the definition of having capacity and whose sole motivation for an assisted death is wishing not to be a burden to exercise that choice. It seems to me that that would be a big step and that the committee would want to think about whether that would be a reason to justify an assisted death.

11:45

In relation to families and young people, there is a question about the degree to which the doctor who makes the assessment knows the family—or indeed the patient—at all. There is no requirement for that, so a doctor who has no knowledge of the patient or the family history, beyond a set of medical notes in front of them, would be asked to make very complex decisions about capacity and motivation.

David Torrance: If a loved one makes a request for assisted dying, should there be a requirement for the family to be informed?

Rami Okasha: I have no evidence on that question.

Amy Dalrymple: We have not done any work on that. Such a requirement would be different to any other treatment. You would know, of course, that that is not a requirement for any other treatment for an adult.

Dr Mills: To speak to Mark Hazelwood's earlier point, not everybody has family and not everybody's biological relationships are their emotional relationships. In some cases, informing the family of any medical decision would be completely wrong and very much against the patient's wishes; in other cases, the family is well informed and the patient would expect and encourage you to phone them. I do not think that it is possible to put down in black and white who should be informed and at what juncture.

I would also argue that such a requirement would significantly increase the amount of time that would be devoted to carrying out the bill's provisions. When I phone family members to have a palliative care discussion, I usually allow half an hour for that, and that is sometimes not enough time; you are already talking about a lengthy process. Then there are the decisions such as whether, once you have phoned first-degree relatives, you should phone second-degree relatives. What about the cousin in Australia? Where do you draw the line?

David Torrance: Thank you.

The Convener: Thank you very much to the witnesses for their attendance and their evidence today.

11:47

Meeting continued in private until 12:21.

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