

Episode 3 Transcript

Topic: DNACPR decision-making and the COVID-19 pandemic

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Guest: Upeka de Silva

This transcript has been edited for clarity

00:01

Welcome to 'Mason Institute Investigates', a podcast series produced by the Mason Institute, funded by the Edinburgh Law School. In each episode we investigate current national and global issues involving ethics, law and policy in health, medicine, and the life sciences.

00:18

This podcast episode contains references to death that some listeners may find distressing.

00:24 Leyla Noury:

Hello and welcome to Mason Institute Investigates. I'm Leyla Noury and I'm joined here by Upeka de Silva to discuss DNACPR decision-making before and during the COVID-19 pandemic. Thank you very much for joining me today and welcome to the podcast.

00:39 Upeka de Silva:

Thank you so much for having me.

00:41 Leyla:

Upeka is the policy officer at the charity organisation Compassion in Dying. Would you like to tell us about what Compassion in Dying is and what their goals are?

00:50 Upeka:

So Compassion in Dying is a national charity that supports people with decisions about end-of-life care.

We run a free nurse led information line and we are the leading provider of advance decisions to refuse treatment. Over the last few years, we've supported over 71,000 people with end-of-life care decision making. I guess our goal is really to help people get the end-of-life care that is right for them and make sure that people themselves are the leaders in their own decision making. So what I'm really passionate about is making person centred care not just a buzzword, but practised in reality, particularly with reference to the Mental Capacity Act.

01:34 Leyla:

That sounds really impressive! So what are your favourite aspects of your role?

01:39 Upeka:

So yes, I work with the policy team and I guess the best part of my job is being able to speak with people about planning and documenting their end-of-life care preferences. I also really like supporting family members when they have to make difficult decisions at the end of life. Interestingly, I also get to look at trends in what callers tell us and use their experiences to influence change. So the topic of DNAR is an example of how we were able to share the realities faced by our callers and then to make change happen.

02:18 Leyla:

So before we dive into this topic, would you like to clarify to our listeners what DNACPR decisions are?

02:25 Upeka:

So firstly, CPR is an emergency treatment and it's used to attempt to restart a person's heart and breathing. And it can be quite an invasive procedure. For example, in hospital less than 2 in 10 people who are given CPR survive and are eventually well enough to leave the hospital. So the reality is that even if CPR is successful, it can sometimes do more harm than good, especially if you are approaching the end of life. So that's CPR. DNACPR decisions which do not attempt cardiopulmonary resuscitation are usually made by a doctor to prevent people from being given CPR inappropriately. This decision is usually recorded on a form and it tells other healthcare professionals about this decision, but

people will still receive other appropriate care. Now the law requires that this decision is clearly communicated and discussed with the patient and/or their family, and the wishes of the patient and the family must be taken into consideration. So, and this is quite important, while the law does not require explicit consent, it does require consultation and communication.

03:44 Leyla:

That's fascinating because people associate CPR with saving lives, but statistics say otherwise. Are DNA CPR decisions a bad thing?

03:55 Upeka:

No, not at all. I think making sure that someone does not get a clinically inappropriate or harmful treatment is definitely good clinical practice. I think many of our callers have shared that inappropriate CPR can be incredibly distressing and it sometimes prevents someone from having a peaceful and dignified death. If, however, the decision is not made on an individual basis and not communicated properly, then it can be distressing but also unlawful.

04:27 Leyla:

So you've mentioned that DNACPR decisions are usually made by a doctor. How do the patient's wishes enter into the decision?

04:39 Upeka:

That's right. So CPR, whether or not CPR is clinically appropriate is usually a decision that the doctor makes. But remember that a lot of people want protection from CPR and everyone has the right to refuse treatment in advance. So people can still make their own decision about CPR, about refusing CPR, and you can do this by completing an advance decision or asking your doctor for a DNAR form.

05:07 Leyla:

So how should discussions regarding DNACPR be approached?

05:12 Upeka:

Ideally, decisions about CPR really should not take place at a time of crisis. And it should be part of a broader discussion about what really matters to someone at the end of life. We know that people feel really distressed when they don't know what the decision means, why it was made and what care will still be provided. We have had so many calls from people extremely anxious after finding a DNAR form in their loved one's records. But after we discuss with them the person's conditions, what quality of life meant to them, many are reassured that this was the right decision. But the problem is, that upset of being denied a respectful or honest conversation still remains, and it's not easy to get over. On the other hand, we also know that clinicians are often really worried about raising the topic of CPR because it can cause upset. But, and hopefully this is reassuring to clinicians, our polling found that if a healthcare professional were to raise the topic of DNAR with people, more than 3/4 would welcome the conversation - even if it was a bit scary. So I think that's really useful to know.

06:31 Leyla:

It's interesting that you mention that such decisions should ideally not be made in a crisis, and that clinicians can be quite reluctant to start the discussion, because right now we are in the middle of a crisis: the current COVID-19 pandemic, which caused roughly 6 million deaths worldwide - almost 200,000 in the UK itself. And last year, the Care Quality Commission (also known as the CQC) released a report that reviewed the use of DNACPR decisions before and during the COVID-19 pandemic. Now as I understand it, Compassion in Dying had also contributed to the report. So could you tell us a little bit about the role Compassion in Dying had in the report on DNACPR decision-making?

07:14 Upeka:

Because we had been dealing with hundreds of questions about CPR before and during the pandemic, we were invited to be part of the stakeholder Advisory Group to support the CQC in their investigations. And because we had supported family members and individuals for a long time, we were able to bring their voices into the discussion. And this is something I feel really proud about and feel strongly about, because it's their voices that really matter when it comes to policy and practice.

07:50 Leyla:

So essentially Compassion in Dying had a very unique position in this review, most notably because you had a lot of contact with the patients and their families. But at the same time, you also observed issues with DNACPR use that occurred prior to the pandemic. And because of this unique position, Compassion in Dying also published their own report into DNACPR use before and during the COVID-19 pandemic. Could you walk us through what both reports found?

08:20 Upeka:

Sure. So the CQC, they undertook a special review because there were concerns raised at the beginning of the pandemic around the use of what is called blanket DNAR decisions across groups of potentially vulnerable people. So they found that while many decisions followed good practice, there's a worrying picture of poor involvement, poor record keeping and a lack of oversight. They found that the right to be involved in decision making was potentially breached in more than 500 cases. So the report highlighted that more work is needed to support health and care professionals to hold conversations. And for me, the most valuable thing was that they called for a cultural shift to ensure that everyone feels supported, to hold open and honest conversations about what they would like to happen at the end of their lives. Very importantly, the CQC found that when done well, decisions are an important aspect of advance care planning. So that was the CQC report.

Our report, the one with Compassion in Dying, so our work really started in 2019 when we had looked at our caller data over the past two years and it had shown inconsistent practice with regards to DNAR decisions. Then we had a huge increase in the number of calls about CPR during the pandemic, so we gathered all of this together, and we found there were three key themes that came out. And I have to say there was good practice and bad practice. So the themes were that the majority of people contacting us wanted protection from CPR. Poor communication and a failure to listen to people's voices caused distress and sadly, unlawful decisions and poor medical practice were not uncommon. But both organisations sort of highlighted 3 areas for improvement and that's why I think it's great that both reports came out together. First was the need for improved support for health and

care professionals; a public health awareness campaign and a consistent national approach to record keeping.

10:57 Leyla:

Now presumably the pandemic had an effect on these pre-existing issues of DNACPR decision-making, but what were the effects of these changes on patients and their families?

11:11 Upeka:

Good question. So I guess it's not surprising that at a time of great stress on the healthcare system and when doctors were working under intense pressure, the longstanding problems of how DNAR decisions are made and communicated were exacerbated. So firstly, and this was highlighted in the CQC report, there were examples of decisions being made about groups of people and it wasn't about individual assessments and decisions. We also found that some conversations were rushed, and people and their families were often not properly involved or given clear information about DNAR decisions. We had many calls from family members saying, "My mum is in a care home and the GP placed a DNAR on her records. No one spoke with me. I don't know what this means." So, the effect of poor communication and not involving patients and their families is a breakdown of trust with the clinical team and this is really difficult to mend.

12:14 Leyla:

This is a side of healthcare that many people would find uncomfortable, listening to the experiences of the patients and their families, but it is vital in understanding how care can be better tailored to each patient. Would you like to share more about your findings and the experiences of your callers?

12:30 Upeka:

Sure. And to be honest, this is sort of, again, like I said, the best part of my job because I get to hear real stories from individuals and their families. So like I mentioned before: people want protection from CPR. The vast majority of calls we got, especially during the pandemic, was about wanting to have a sense of control over what their death and dying would be like. I had, for example, a lady said, "I'm worried that CPR will crush my ribs. I just want someone

to hold my hand. If I'm dying. If God is ready for me, I am ready for him." And then we had callers sharing how upsetting it was when their concerns and treatment preferences were dismissed and they were ignored. So somebody said to us, "My sister asked about her DNAR at the hospital and they said: "this is a hospital, not a hospice. We make people better." So they felt really dismissed and ignored and they didn't know where to turn. And something that we don't hear much about, but is incredibly important, is to be aware that inappropriate CPR can cause distress and can deny people a peaceful and dignified death. So if I may, let me read this story from a lady who said,

"My husband was 81 when he died. He had many health complications. He said to everyone who would listen that when he died he did not want to be revived. This must have been recorded. One morning he collapsed in hospital. Within half an hour I was there, but the crash team were already hard at work. I heard this terrible thumping. I screamed at them, "Stop, stop. He didn't want it." They should have known his wishes. He wanted dignity, but he was deprived of it. They apologised profusely later, but the sound of that machine thumping away, pummeling his chest, was deeply upsetting and unforgettable."

So while the minority of people we speak with are genuinely upset by the decision, other people are upset by the lack of communication, not the decision. For example, this lady said,

"My husband was admitted to hospital with chest problems and had various tests before he was discharged. When I arrived home, I looked in the discharge bag and I was very surprised to see a DNAR form stating that this had been discussed with my husband and myself. Absolutely no such thing occurred. My husband was fully aware of everything that was going on, and I would certainly have remembered such a conversation. I'm not suggesting that a DNAR was inappropriate, but it came as a real shock to read without any warning."

So I'm sorry that these were slightly sad stories, but what is important is that it doesn't take much to get it right. When decisions are shared, the experiences are better. So this lady said to us,

"My 91 year old husband was in hospital suffering from COVID. The registrar was very helpful. We discussed resuscitation fully and agreed to let my husband die peacefully. I was impressed by the time and consideration shown to me."

16:02 Leyla:

These stories are extremely profound, and clearly the importance of communication in DNACPR decision-making cannot be understated. But why was it difficult to establish the right kind of communication when making decisions about DNACPR?

16:19 Upeka:

I guess there are two key problems. Like I mentioned earlier, many clinicians don't feel confident discussing CPR in a way that is open and supportive and on the other hand, there's a general misunderstanding about when and why these decisions are made and the success rates of CPR. So there's two sides to that issue. And if I may, there is an overall problem which goes beyond DNAR, which is that I think there is insufficient focus placed on enabling people to make their own decisions about their end of life care. From our polling we know that 76% of adults have very strong feelings about the end of life. But only 7% have made either an advance decision or a lasting power of attorney. And this is something that Compassion in Dying is really working to change.

17:16 Leyla:

So far, what has been done to remedy these problems?

17:19 Upeka:

Well, there's been quite a lot of good things happening already for a while in fact. There's the ReSPECT process. It's called Recommended Summary Plan for Emergency Care and Treatment. And it's a national, standardised process which focuses on developing a shared understanding of a person's overall goals of care. So like I said before, not just about CPR because that's one treatment, but your overall goals of care and what matters to people. Wales and Scotland have a standardised approach and form to CPR decision making. The NHS website has new guidance on DNAR, which is very good and written well. And in March this year, the Universal Principles of Advance Care Planning was published by NHS England and Compassion in Dying contributed to this, and it really sets out the importance of person centred care; honest conversations and the importance of sharing and using advance care plans.

18:30 Leyla:

That sounds good, but is that enough? Is there anything else that could be done, or improved on?

18:37 Upeka:

I guess it's ongoing. There's always something that could be better. For me, I can think of four key areas really. One is that we really have to get the pure, honest facts out there. CPR can often, but not always, do more harm than good. The decision is a clinical one that requires discussion and the offer of a second opinion, but not consent. Those are things that people really need to know more about. Secondly, I think health care professionals need more support to enable them to explain what CPR is and why it may cause more harm than good for a particular person. And I guess they need reassurance that people are willing to have this conversation and I hope that our polling contributes a little bit to that reassurance. Thirdly, I think conversations about what matters to a person really should happen early. We cannot wait till the last moment or for a crisis to discuss what treatments will and will not work and will and will not matter to the person; and conversations are not enough. It absolutely must be written down if they are to be respected and followed and that's why advance decisions, advance statements, lasting power of attorney, DNAR forms, are all really valuable. And finally and one of the biggest concerns some of our callers have is that they're worried that their plans will not be known about and therefore followed, so record keeping and sharing really must be improved. So if someone has a DNAR decision, it really needs to go from their care home or their home, to the ambulance trust, to the GP, to the hospital, it needs to follow them and this is something that needs working on. I guess underlying all of this should be an understanding that when done well, DNAR conversations really help people understand what is likely to happen if they become unwell, and give them the opportunity to ask questions and explain what matters to them.

20:59 Leyla:

I really hope that this will encourage our listeners to have those difficult conversations with their clinicians and care givers. I just have one last question to ask. Do you think there is a fear of talking about death?

21:11 Upeka:

Just before I answer that, I wanted to say that we should start saying these are important conversations. Because as soon as we say it's difficult, then it becomes difficult. So there's our message. No, I don't think there is as much fear as everyone says. My personal opinion is that it should be a taboo to say that talking about death and dying is a taboo. We did a survey in 2019 with 502 people living with advanced or terminal illness and 58% said it was not a taboo subject for them. What stopped them, really, was the assumption that other people will be upset by it. But most of them found these conversations liberating. I also know from our information line and our community engagement work, that when given the opportunity to speak freely in a safe and nonjudgmental space, people love to share their thoughts and feelings about death and dying. And trust me, people really do have strong feelings about what they do and do not want at the end of life.

22:28 Leyla:

Thank you very much for taking the time to share your organisation's research on DNACPR decision-making before and during the COVID-19 pandemic.

22:37 Upeka:

Oh, you're most welcome. It was a pleasure and thank you for the opportunity.

22:41 Leyla:

Thank you very much. Upeka de Silva, Policy Officer at Compassion in Dying. You've been listening to our podcast, Mason Institute Investigates.

22:52

Thank you for listening to this podcast. We hope that you enjoyed it. For further information, check out the links in the show notes of this episode. In the next episode, Professor Farrell returns to talk with Dr Sarah Devaney from the University of Manchester about current proposals for reform of the clinical negligent system and their implications for patient safety. See you next time!

Transcribed by Leyla Noury