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This is a text version of a podcast from Pedscases.com on "**Medical Assistance in Dying: A Paediatric Perspective – CPS Podcast.**" These podcasts are designed to give medical students an overview of key topics in pediatrics. The audio versions are accessible on iTunes or at www.pedcases.com/podcasts.

MEDICAL ASSISTANCE IN DYING: A PAEDIATRIC PERSPECTIVE – CPS Podcast

Developed by Dr. Chris Novak and Dr. Dawn Davies for PedsCases.com
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Introduction

Chris: In June 2016, the government of Canada introduced Bill C-14, allowing physicians in Canada to provide medical assistance in dying (MAID) to eligible patients. Since that time over 2000 patients have ended their lives through this process. Under this legislation, a patient has to be suffering from a "grievous and irremediable medical condition" causing "enduring and intolerable" suffering. The patient has to have capacity for consent, and be over the age of 18. For pediatric care providers, this has left a number of questions, with strong feelings on both sides of the issue. Could medical assistance in dying ever be an appropriate option for children and adolescents in Canada?

My name is Dr. Chris Novak. I'm a second-year Paediatric resident at the Stollery Children's Hospital at the University of Alberta in Edmonton. This podcast was produced by PedsCases and the Canadian Pediatric Society (CPS), and will be discussing the new CPS position statement titled: "Medical Assistance in Dying: A Paediatric Perspective." I'm joined today by the lead author of the statement, Dr. Dawn Davies, a Paediatric Palliative Care specialist and Associate Professor at the University of Alberta. Welcome Dr. Davies and thank you for sharing your expertise on this topic! To start, could you tell us a little bit about your background, and how you became involved in writing this statement?

Dr. Davies: At the time of the Carter vs. Canada decision in 2015, I was just taking over as the chair of the CPS Bioethics Committee. I really felt that given that mature minors make a lot of their own healthcare decisions, especially in the context of a serious illness where we don't have effective therapy and we know that the patient will die, that the concept would come to mature minors sooner than later and I started the statement at that time.

Learning Objectives

Chris: Thank you so much for joining me! The objectives of this podcast are to:

1. Discuss the current state of MAID in Canada
2. Review how other jurisdictions have addressed this issue in pediatric patients.
3. Review current issues regarding MAID for children and youth in Canada
4. Review the CPS recommendations in this position statement.

Clinical Case

Chris: To put this in context, I was wondering if you could share a few examples of clinical cases where the topic of MAID may arise in pediatrics.

Dr. Davies: To avoid identifying a patient I'll just speak in generalities. Some areas where my colleagues and I have seen this arise is in older children with end-stage diseases such as cystic fibrosis and advanced cancer. Parents of children with really progressive neurodegenerative conditions, or newborns with painful congenital conditions like epidermolysis bullosum, or multiple congenital anomalies where a child can't even clear their own secretions and is frequently coughing or choking. Those are just a few examples where we might expect this question to arise.

MAID in Canada

Chris: I've heard so many terms used to describe MAID. Could you review some definitions and why MAID has become the term of choice in Canada?

Dr. Davies: Initially, the term was physician-assisted dying, but since then there was a realization that in many parts of Canada, especially remote parts of Canada it is really care by nurse practitioners. With the inclusion of nurse practitioners in the legislation it was expanded to the term MAID rather than physician assisted dying.

Chris: I understand in Canada right now MAID can take one of two forms: either euthanasia or practitioner assisted suicide. Can you explain the difference between the two?

Dr. Davies: Sure. Euthanasia, in the most simple terms, is when at the patient's voluntary request, a practitioner administers the medication that causes the patient's death. That is usually done by intravenous injection. Practitioner assisted suicide (PAS) is where the patient voluntarily makes the request, and the practitioner prescribes the medication that a patient can self-administer to cause their own death at some later time.

Chris: Are both currently options in Canada for patients?

Dr. Davies: Yes. However, in Alberta less than 1% of patient have elected to go with the practitioner-assisted approach, with the huge majority of patients opting for euthanasia.

Chris: Could you tell us more about the process to evaluate a patient for MAID?

Dr. Davies: Currently in Canada, Bill C-14 states that the patient must be greater than 18 years of age and capable of making their healthcare decision. They must have a grievous and irremediable medical condition, which essentially mean they have to have a serious and incurable illness. They need to be in an advanced state of that illness, and have irreversible decline. They also have to experience enduring and intolerable suffering, either physical or psychological. Lastly, their death needs to be reasonably foreseeable. In addition to that, they need to make a voluntary request for MAID. This means we need to ascertain that nobody is influencing them to make this decision. We also need to make sure that they are capable of giving informed consent. This needs they need to have been informed of all other means of relieving their suffering including palliative care. At this stage, children, including mature minors, are not eligible for MAID.

Chris: The CPS statement breaks up conversations regarding MAID in children into two categories. Mature minors, and never-competent children or youth such as young children or those with severe disabilities. Could you tell us more about the concept of mature minors and how that concept is applied to other areas of healthcare?

Dr. Davies: I'll start by saying that the notion of mature minors only applies outside Quebec. The civil code in Quebec does not legally recognize the concept of a mature minor. Having said that, minors there can make a lot of their own healthcare decisions over the age of 14, but if the child is in hospital for more than 12 hours, their parents need to be notified and if the consequence of the decision is serious and may result in harm the parents need to be involved. So, they do have somewhat of a notion, but they don't legally recognize it the same way.

In the rest of Canada, we have a well-entrenched notion of a mature minor. This will be an older child, usually an adolescent, who basically has the maturity of an adult for decision-making purposes and that would be both cognitively as well as emotionally. In addition to having that capacity we need to make sure that their decision is voluntary. That is basically the crux of it.

Chris: From what I understand this has become a very controversial part of this legislation in Canada. As it stands right now, how is the government of Canada assessing MAID in regard to mature minors?

Dr. Davies: The preamble to Bill C-14 stated that there needed to be independent review of the issue of mature minors, in addition to those with mental illness as the sole reason for the request and the group of people who may wish to make an advanced request for MAID assuming they may lose their capacity at some future time. The

Council of Canadian Academies is an independent body of the social sciences, healthcare and engineering that comes together to form a council. They have been charged to do an independent review for these three controversial groups. It is being done through an expert panel of about 44 people with varied backgrounds. Lots of people have commented that this a completely academic focus. I would disagree with that because there are clinicians from all areas of healthcare as well as people well-versed in constitutional and health law, as well as people with a strong psychology/sociology/anthropology background. The charge is to look at all of the ramifications both for persons themselves as well as the society through all of those lenses. We need to see what is the evidence and then present that evidence to the government by the end of 2018. Then legislators will have to examine the evidence and draw their own conclusions from it.

Chris: Have there been any conversations about younger children, or never-competent minors?

Dr. Davies: There haven't been. It's important to point out that since the Carter case onwards there has never been any discussion about the inclusion of people that cannot voluntarily request MAID for themselves. The reason that we decided to ask our membership in the CPS about this, is that we knew we would only have one opportunity to do so. In my practice in palliative and checking with my colleagues across the country it did seem that conversations were occurring with parents, and that specific and explicit requests were coming from parents of very young children we wanted to data about that notion in our surveys.

MAID and Pediatrics in Other Jurisdictions

Chris: Several other countries, including the Netherlands, Belgium and certain part of the United States have offered MAID for several years. How have other countries address the question of MAID in pediatrics?

Dr. Davies: How they got there is a little bit elusive, even if you look at the literature. It is only the Netherlands and Belgium that offer MAID to some categories of minors. In Holland, the most controversial development was of the Groningen Protocol which was published in the New England Journal of Medicine in 2007. This was a situation where they call it "deliberate ending the life of a newborn" because the neonate isn't consenting and isn't voluntarily requesting it. The criteria state that the neonatologists and parents must agree that there is "hopeless and unbearable suffering of the infant" and that the babies are deemed to have no chance of survival, or a minimal chance of survival, but with poor prognosis and with poor quality of life. That's the only jurisdiction that allows MAID for infants, and is the only place where the decision isn't voluntary.

The Netherlands and Belgium also extend MAID to mature minors. It's important to point out that this has been accessed very infrequently. In Belgium, as far as I'm aware there has only been one such case, and in the Netherlands, there have only been between 5-7 cases, so this is a very small minority of patients. It's also important to

know that in some of those jurisdictions they do allow MAID for adults with conditions such as a mental illness or an intolerable physical disability, but children under 18 must have a terminal illness that they will be dying from in the short-term to access MAID. So, there is more restriction with MAID for minors.

Canadian Paediatricians and MAID

Chris: Dr. Davies, I understand that you have been involved in two Canadian studies relating to MAID and Pediatrics. The first looked at the incidence of requests for MAID from minors or their parents. Could you tell us about your findings?

Dr. Davies: These studies were done in conjunction with the Public Health Agency of Canada through the Canadian Pediatric Surveillance Program (CPSP). We sent it out to our membership of 2600 members, and we had 1050 respondents which is a response rate of about 40%. Healthcare professionals reported discussions with 60 minor patients in the preceding year with a total of 17 explicit requests for MAID from minors. In the same time frame 118 participants reported having conversations with the parents of 419 never-competent patients with 91 explicit requests for MAID for their children. It's important to state that there was no regional variability, and that this was similarly prevalent across the country.

Chris: So, it was far more common for the parent to request on behalf of their child rather than the child themselves?

Dr. Davies: That's right. Whichever way you look at it, whether it's explicit requests or exploratory conversations it's in the order of a 5-fold difference favoring parents having the conversations more than children. This is perhaps unsurprising given that a lot of the really devastating things that happen in childhood happen in early childhood.

Chris: The second study, evaluated Pediatricians values regarding MAID in children and youth. What did you find?

Dr. Davies: The CPS-Attitudes survey went out to a slightly smaller group of 1979 participants. Unfortunately, we had a poorer response rate with usable data from 29% which was 487 respondents. Having said that, almost half (46%) actually favored extension of MAID to mature minors who could make a voluntary request with the proviso that they had a progressive or terminal illness. Fewer actually believed that this should be extended to mature minors with intolerable disability at 29%. There was a very strong apprehension about not extending MAID to minors with mental illness with only 8% support. On the other hand, about a third of all respondents said that MAID should never be extended to minors under any circumstance. As you can see there has been a lot of polarization about this debate.

Chris: Did the Attitudes survey ask about Pediatricians willingness to actually provide MAID to minors themselves?

Dr. Davies: They did. It was not surprising to me to see that only 19% of respondents said that they might consider personal participation in MAID. We know from other surveys in adults that more physicians say in surveys that they would consider participating then the numbers bear out when we look at how many doctors are actually participating. I think the actual number would probably be lower than that – just guessing.

Recommendations

Chris: Let's review what we've discussed so far. We reviewed the current state of MAID in Canada including the requirement that patient be a competent adult suffering from a "grievous and irremediable medical condition." We've discussed two different pediatric groups, mature minors and never-competent minors, and explored the precedent set by other countries including the Netherlands and Belgium. Research from CPS surveys show that this is an important conversation, as pediatric care providers are having both exploratory conversations and explicit request for MAID in pediatric patients. They also found that there is currently not a strong consensus among pediatricians about whether or not MAID should be accessible for children. With all of that in mind, what bottom-line recommendations has the CPS made in this position statement?

Dr. Davies: I think it's one of the few position statements where we actually couldn't take a clear position at this point. I think that some important points did come out. There was a strong response from our members that there was an under-emphasis on palliative care for children. One of the main recommendations is that were MAID extended to mature minors, then we really need to design, fund and deliver child and youth-focused palliative care as a priority across Canada. I think that secondarily we really feel we need to evaluate and learn from the current MAID policies and experiences for adult patients and their families both in Canada and elsewhere. Also, we really need to have an extensive consultation with the people who are going to be most affected. While physicians and clinicians are one facet of that discussion, we need to talk to affected teenage patients and children who have serious illness, and the parents of those children, as well as parents who are bereaved after the death of a child through such an illness. At higher levels, we are encouraging governments at every level to develop policies and procedures that would safeguard young people from the possible risks and harms if MAID were extended given their unique vulnerabilities. It's also very important that clinicians know how to assess a minor's capacity to make their own personal health decisions, and we plead that the decision-making about capacity still rest with the child's clinical team. Lastly, we are just asking for respect from all parties for all parties. From a physician perspective, we would ask for respect in the right not to participate in MAID, but similarly if the law is changed and mature minors are considered, then I think we really need to respect our colleagues who feel strongly that they would like to participate as far as the law would allow.

Chris: Thank you. Looking forward at the next months to years, do you think any further research needs to be done to explore this question.

Dr. Davies: Absolutely. We are just scratching the surface. Bill C-14 is pressurizing the debate around MAID. I think that we really need to have robust data from the adult experience and learn from things that don't go as well as they should. I think that there needs to be a lot more work just in the medical community itself about how do we do capacity assessments. That's something I hear from my colleagues in private practice or smaller rural settings that they feel very unprepared at the end of their training to feel comfortable doing that kind of capacity assessment. So, I think a lot more data is needed and I think that there's really no limit to the kind of research that could be done to make sure that we stay on a safe path that benefits everyone.

Chris: Do you have anything else that you'd like to share today?

Dr. Davies: I think that's it for now. It's evolving very quickly, so I would look forward to participating in another podcast should things change substantially.

Chris: Thank you to Dr. Davies for sharing your experience and expertise. We hope that this PedsCases podcast has been helpful. Thanks for listening!

References

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