INTERVIEW SPOTLIGHT
DR. DAVID LYSECKI

AN INSIGHT INTO PALLIATIVE PEDIATRIC CARE

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Pediatric palliative care is often an overlooked field of medicine. As terminally ill children make up a small proportion of patients in Canada, a less robust network of resources is available to deliver end-of-life care for these patients. To gain a better insight into this field, we sat down with Dr. David Lysecki, a pediatric palliative care physician at McMaster Children's Hospital. He is also the founder and head of the Quality of Life & Advanced Care program at McMaster Children's Hospital and the Division of Pediatric Palliative Medicine in the McMaster University Department of Pediatrics.

WHAT IS YOUR BACKGROUND AND HOW DID YOU COME TO BE INVOLVED IN PEDIATRIC PALLIATIVE CARE?

I went to medical school at McMaster after undergrad at University of Toronto. I entered my pediatric residency at Queen's, [where I] became interested in both pediatric oncology and pediatric palliative care. I pursued a fellowship at the Hospital for Sick Children in pediatric hematology oncology […] and joined McMaster Children's Hospital as a pediatric palliative care physician and oncologist in 2015. In 2018, I transferred over to [...] full time palliative care.

WHEN DO YOU TYPICALLY SEE PEDIATRIC PALLIATIVE CARE BECOMING INVOLVED IN A PATIENT'S CARE?

Palliative care has two connotations: one is the palliative care specialist resources, and the second is the approach to care that brings a focus on quality of life, [which] takes a holistic family-centered approach and recognizes when mortality is a risk or impending. [The time] when pediatric palliative care becomes involved is dependent on the family scenario [and the] comfort of the patient, but often we do our best work when we are involved at diagnosis. [We] support a family from the time of diagnosis with decision making and symptom management all the way through to a child's end-of-life or transition into the adult world. Our program can happen as early as *in utero*, where we do prenatal consults for a fetus that's been diagnosed with a life-threatening or life-limiting condition and support the family through that journey *in utero* and after birth, whether the child lives for moments or for decades.

WHAT DOES THIS CARE TYPICALLY LOOK LIKE FOR THE PATIENT AND THEIR FAMILY?

Our first priority and our role is about the quality of life of the child [which] can be divided into two aspects. [Firstly,] there are negative things that take away quality of life or cause suffering, [which] we try our best to eliminate, [whether] they be physical, spiritual, social, emotional, or psychological. We also try to find ways to increase [...] quality of life and opportunities for joy [by] helping families navigate the system and [problem solve] so that school, extracurricular activities, wish trips, special family moments and experiences can [be fostered]. Our program here is called "quality of life and advanced care", or "quality care", and [so] the second aspect of that care is around care planning, advanced care, and peace. So while we look at quality of life now, in the moment, we also look at quality of life in the future and challenges that may be ahead of the child, as anticipated [by] their medical teams and the literature. [We] ideally help families plan for [these challenges through] symptom management plans, advanced care plans if the child is critically unwell, technologies to support the child's life, or to accept the limitations on the child's life and ensure their comfort as they pass away.

There is a need for experience and expertise to guide the family through those last moments, hours, [or] weeks, and support them with compassion, with forewarning about what to expect, treating symptoms as they arise, preparing for the end of life and discussing things like organ and tissue donation, funeral planning, or an autopsy. We also play a role in bereavement follow-up to support families ensuring that they end up with a nest of support around them which may come from professionals [or] community members. I think it's a really important role that we play, because if there are unanswered questions or uncertainties that the family holds [as] they go off into the bereavement world outside of the acute health care system, they may never be able to get the answers that they're looking for in the community. [Therefore,] we try to bridge that gap [through transitional bereavement support. The parents might ask:]

"Remind me, what were the findings on the MRI again? Why did we make this decision?"

"You know, I gave this medication —is there any chance that medication could have contributed to the end of life?"

[These] questions come up, even sometimes when deep down a parent knows that [it] isn't the case, [but] sometimes they really need to hear that to stop those thoughts from running through their head. We really focus on those things, trying to make each day the best day it can be, by being prepared for the next day and acknowledg[ing] that our journey with them may be days or decades.

WHAT DOES THE PEDIATRIC PALLIATIVE CARE TEAM LOOK LIKE?

A fully functioning palliative care team should be able to support the biological [and] biophysical needs of families. It's important to recognize that grief isn't something that happens only after someone dies. Grief is something that occurs every day throughout that journey. So when we talk about a pediatric palliative care team, I would say that all families should have the care around them to support [their] needs, [including] physician support, nursing support, social work, a care coordinator, and child life specialists, particularly for other siblings, but also for the child themselves. [Teams can also involve] a spiritual care advisor, and someone doing bereavement support, who [don't] necessarily have to be health care professionals. [A support] network will probably look different for every child and family based on their unique circumstances, but ideally, a specialist pediatric palliative care team has all of those roles [to fill in] when there are gaps in their network. Our team at McMaster Children's Hospital has three full time positions: one full time care coordinator, a 0.6 FTE nurse practitioner with a focus on perinatal palliative care, and [...] a child life specialist to support our families.

WHAT ARE SOME COMMON CHALLENGES THAT YOU'VE ENCOUNTERED DURING YOUR TIME WORKING IN PEDIATRIC PALLIATIVE CARE?

First off, we all acknowledge that this isn't fair, and it shouldn't be the case where children don't have the opportunity to grow up [and] live long, where parents outlive their children. It is unfortunately the reality that we have to accept and focus on the things we can control. However, grief can act as a major barrier to a therapeutic relationship, as families may be reluctant to have advanced care conversations or to think about the future for their child, often [from] fear and anxiety. Sometimes the right way to approach this is to first address the grief, normalize them and accept them, and support the family as we guide them through the decisions in advance with clear minds rather than then deciding in a crisis. [Another challenge involves] apprehension about communicating with children about their condition. [The literature shows] that when informed in a developmentally appropriate manner and [provided] with support, most children cope and do better with the information rather than them being left to wonder. Children are very intuitive [and] pick up on signs from their parents [and] their medical team. [Lastly] I would also just highlight that our medical system isn't particularly designed for the unique needs of these families in particular; our system is typically very jurisdictional-based. We've got all of these borders and boundaries and these families are often dependent on a pediatric tertiary centre, but often live in these small communities. They bounce back and forth, [making it] challenging for [family members] to see their family doctor and look after their own health, particularly because they inevitably prioritize the needs of their children. Our families or parents continuously sacrifice their own health and well-being. We are always striving to not only support our patients better, but [also their] families.

HAVE YOU NOTICED OR ENCOUNTERED ANY COMMON MISCONCEPTIONS WHEN IT COMES TO PALLIATIVE CARE, PARTICULARLY IN THE NEONATAL AND PEDIATRIC SETTING?

I think the most common misconception is that palliative care is end-of-life care and [is incompatible] with chemotherapy, surgery, and life-prolonging interventions [like] intubation, ventilation, and ICU admissions. [In reality] there really isn't an either/or, [since] palliative care is a focus on quality of life. There is no reason that a child or an adult shouldn't have access to high quality physical symptom management, emotional support, psychological support, [and] spiritual support during their hardest times, when we can recognize these needs [in advance]. Study after study comes out showing that palliative care is actually cost-effective; [that] by providing families with the right support at the right times, we can often mitigate unnecessary hospital admissions [or] procedures, when families are fully counseled about the possible outcomes of that procedure within the context of their goals of care. [Ultimately], I feel that the cost of palliative care is a very valuable area to invest in, because you get better care, typically for less money.

WHAT ARE SOME OF THE WAYS YOU CAN SEE THE FIELD EVOLVING TO BETTER SUPPORT PATIENTS AND THEIR FAMILIES?

There has been great evolution in the field over the past 25 years. I would say that the most important area is [...] the topic of equity. Let's take Vancouver [for example, which] opened the first children's hospice in North America in 1995, that offers amazing support to children and their families around them in life and death grievances. From prenatal issues to over 18, that model exists in Vancouver, [but] there are a lot of places in Canada where there are next to no supports. [...] The other related challenge is that [...] children represent about 1% of all people requiring palliative care. [Therefore], outside of major cities, you're [typically] not going to have the need for full scale interdisciplinary pediatric palliative care teams in every small community. There needs to be partnerships between strong [and] robust teams at tertiary hospitals and community providers to support people across the vast map of Canada. Virtual technologies have really improved our ability to do that. But areas where there [aren't] robust interdisciplinary pediatric palliative care teams don't have that skeleton backbone upon which to build a network of support across their catchment.

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