

Transcript of RELIEF podcast with Christine Chambers:

RELIEF: Hello, and thanks for tuning in to RELIEF podcast series. I'm Neil Andrews, editor of RELIEF. I'm really thrilled today to have the opportunity to chat with Professor Christine Chambers. Professor Chambers is a professor in the Departments of Pediatrics and Psychology and Neuroscience at Dalhousie University in Halifax, Nova Scotia. Her studies have focused on the role of developmental, psychological, and social influences on children's pain, and she's been particularly focused recently on the role of families in children's pain, and on using social media to spread knowledge about health and information about health, particularly children's pain, and she's here today to talk to RELIEF about some of her research in these areas. Professor Chambers, welcome to the podcast. Thanks for being here today.

Christine Chambers: Thanks for having me.

RELIEF: Why don't we start from the top: How did you become interested in studying children's pain?

Christine Chambers: Very much by accident. I had always wanted to be a child psychologist. I read a book about child psychologists when I was 12 years old, and when I got to university I met with an undergraduate advisor and I asked, how do I become a child psychologist, and he said, well, you're going to have to do your PhD. If you want to get into a PhD program, you should probably get involved in research. The only child psychologist doing research in my department studied children's pain, so that's very much how I fell into this area and then became absolutely fascinated by the potential, and also the story around how children's pain has not been adequately managed over the years. It's been a pleasure to be a part of research to try to better that problem.

RELIEF: Talking a little bit more about your current research, you study the role that parents and families play. So, can you talk a little bit about that: what does the research show about the impact that parents and families have on the pain that children experience, and are there any overarching themes that have emerged from the research?

Christine Chambers: Right. That's been a real common thread to everything I've done over the last 20 years, trying to understand more about the role of parents and how parents can be best utilized and best engaged as part of the team in delivering proper pain care. Some of our studies have looked at creating tools to help parents better assess their children's pain, for example, after surgery. We've done studies looking at how parents manage their children's pain at home, for example, after day surgery.

We've also done a lot of research trying to understand more what parents say and do when their children have pain, and how that impacts their children's pain. For example, one study out of my lab, and others have found this as well, is that when parents reassure their children when they have pain, it actually is related to increases in child pain and distress, which is a bit counterintuitive, and some of our studies have disentangled that

it's because kids think their parents are anxious when they reassure, and that makes kids feel worse.

Those are just some examples of the kinds of studies that we've done to really try to just get at what is this relationship between the role of parents and children's pain experiences, and then how can we optimize parents' roles.

RELIEF: Great. Now, one example from your own research recently of parents playing a role in their children's experience of pain is procedural pain, so when kids are undergoing procedures, medical procedures such as vaccinations. Why did you decide to focus a little bit on this area?

Christine Chambers: Vaccination pain has been a really important area of work of ours over the last couple of years, and it's been wonderful to collaborate with my colleague, Anna Taddio, who's based in Toronto, who has led a lot of work in the area of vaccination pain. She has a large team of scientists and stakeholders involved. The reason we focused on vaccinations and have a particular interest in medical procedures is that one in ten children develop a significant fear of needles that often interferes with their ability to follow routine medical care. Parents sometimes have a lot of difficulty getting their children to medical appointments, and even though we don't hear about it as often as other reasons in the media. For example, being afraid of needles and being afraid of pain from needles is a reason why children don't get vaccinated. So, this is an important health issue and we're hoping that our work in the area of vaccination pain, where we've identified very effective strategies to help children decrease vaccination pain, where we hope that these strategies will be able to be implemented and make a difference.

RELIEF: To what extent has vaccination been a problem, in terms of kids not getting vaccinated? Is it a widespread problem in Canada? Are there any statistics for it, any statistics for the US and maybe other places in the world?

Christine Chambers: Yeah. Vaccine hesitancy, as we would refer to it, is sort of a global health issue, and there's not a lot of really firm data on the role of pain and poorly managed pain as part of that. When you ask parents why they aren't taking their children to get vaccinated, it's one of the top 10 reasons why parents identify vaccination pain as a barrier. It is, interestingly enough, the one area where we have evidence to make it better. There are lots of reasons why parents aren't getting their children vaccinated, and there are not necessarily easy evidence-based fixes for those, but when it comes to pain management, there are things that we can do now that we know, based on the research, are proven pain control.

This is partly why the World Health Organization reached out to our group and asked us to come and share with them some of our recommendations for vaccination pain management, and some of these recommendations have been rolled out globally.

RELIEF: Before we get to discussing one of the initiatives in this area that you're involved in, *It Doesn't Have to Hurt*, what does the published literature say about what works to reduce vaccination pain and needle fear?

Christine Chambers: There are fortunately lots of effective strategies that we've identified, so we have summarized these in a series of systematic reviews and we have a clinical practice guideline for managing vaccination pain. Some of the strategies vary by age, so, for example, for babies, just even simple breastfeeding during vaccination is analgesic. It reduces pain. Use of sucrose, which is essentially sugar water, in babies under the age of 12 months also reduces pain.

For older children, using topical anesthetic creams like EMLA, for example, applying those to the skin usually about an hour before their procedure—that can significantly reduce pain; using distraction, so taking kids' minds off of it; making sure that families and clinicians are prepared and educated; and there are some simple things from the technical side, from the administration side.

For example, when children require more than one vaccination in one visit, there are some vaccinations that are more painful than others, so by injecting the least painful vaccine first, it actually means the overall pain response is less than if you injected the most painful vaccine first. That's just a simple strategy. There are also physical strategies like holding a baby in your arms rather than laying them out on an examining table for a vaccination, [which] impacts pain, and likewise, having older children seated upright rather than lying down, studies have shown that that is related to decreases in pain.

RELIEF: Another way that you are addressing this issue is, as I mentioned, you've started a program called *It Doesn't Have to Hurt*. Can you describe what this initiative is?

Christine Chambers: Sure. As a scientist, I've been publishing my research in journals and going to conferences, all with the hope of making a difference for children with pain, and certainly that's why I wanted to be a child psychologist in the first place, to help families, but it's only been in recent years that I've realized we have what we call a knowledge-to-action gap in the literature, and it's not unique to pain or vaccination pain. We have these gaps across health areas where there's all this incredible science, but what actually happens in practice lags behind.

There are estimates that it can take as long as 17 years for research findings to get into the hands of people who can use them. I started a fellowship program actually that was funded by the Mayday Pain and Society program, in which I wanted to reach parents with research evidence about children's pain, and I decided to use social media to do it. Parents are heavy utilizers, both moms and dads, of social media for health information, and we wanted to be able to harness that power and get parents the information that they could use.

It started with a YouTube video that I created with a communications company, in which we shared three simple strategies that parents could use to help their children with needle

pain. Since that initial video, we have engaged in a partnership with an online parenting forum in Canada, Erica Ehm's yummymummyclub.ca, and they have a reach of over five million parents a month. Together, over the last year and a half, we have been creating all kinds of great digital content for parents: blog posts, Instagram images, Facebook polls.

We provide the science, so we have a team of scientists. Parents are engaged in the entire project. They help select the topics and help shape and vet the content before it goes live, and then our partner, YMC, creates all of this beautiful content and then pushes it out over their communications channels so that it actually get into the hands of parents who can use it.

RELIEF: This social media approach you mentioned was used because it will reach people who are using social media. Was it challenging as a scientist to use social media? I believe there's some resistance among scientists to use social media like Facebook and Twitter. Can you just describe just a little what your experience has been using social media to get this content out there?

Christine Chambers: Right. It's interesting. I mean, my own experience has shifted and I have seen the attitude in the scientific community about social media really shift, as well, in recent years. The video that I sort of led, we put online in 2013, so just over three years ago. I learned the hard way that if you build it, they do not necessarily come, and it was very hard for me to first of all think outside my scientist box and approach creating that video in a creative, different way. Fortunately, I was able to work with a communications company on that.

Second of all, getting it in front of people is really hard. Scientists are good at science. We're not necessarily really good at creating digestible content for parents and also reaching them, so that's where the idea to do this in partnership with a forum that has already got a credible online presence, that already has the reach of parents and knows how to effectively market to parents. This partnership has been very effective and certainly been more successful than anything I could've done on my own.

I do think there's still this stigma in the scientific community around social media. I've had a lot of work rejected from conferences, people saying, well Christine, this isn't really science, but there've been a couple of influential pieces written in the last couple of years. *Nature* had an article recently about the role of science and social media, and so I think people are starting to pay attention to the power here, and I think that's a good thing.

RELIEF: Great. What are some of the main findings or outcomes that you've seen so far with *It Doesn't Have to Hurt*?

Christine Chambers: The grant-funded portion, this was funded by a Canadian Institutes of Health research grant, so the grant-funded portion wrapped up in September, and we're just in the middle of pulling our analytics and doing our evaluation right now. In terms of reach, our content had over 130 million views worldwide, which is

wonderful, certainly far more people than I could have ever reached on my own. Our preliminary analysis, looking at parents' awareness and use of research evidence about children's pain, shows significant increases in the degree to which parents were aware of and using strategies for parents.

We also are evaluating the partnership itself because we think that this kind of collaboration of scientists working with online media could be a very effective model for mobilizing different types of research evidence as well.

RELIEF: Good. I know also that you expanded It Doesn't Have to Hurt to look at other areas of pediatric pain. What other areas are you looking at and what things are you doing in that realm?

Christine Chambers: We've heard from so many parents over the last year that we've been engaged in this project, which is one of the things I love about social media. I mean, it's not just a one-way push-out. It's a chance to have a conversation with parents and to really plug in to what parents are looking for. Many parents said, we appreciate your content, which for It Doesn't Have to Hurt was geared very much at a public health level. We covered pain issues that many parents would face, or the majority of parents would face, things like vaccination, day surgery, headaches and stomach aches, ear aches, those types of things.

We did hear from parents whose children have special conditions or chronic illness, who said, we would like to learn more about what is known in the scientific literature about pain in particular areas. We do have sort of a sister campaign called Kids' Cancer Pain, Making Cancer Less Painful for Children. This again is a partnership, this time with the Cancer Knowledge Network, which is an online education forum for cancer patients and caregivers, and it's funded by the Canadian Cancer Society.

We're using a similar approach. We are engaging with parents, finding out what content would be helpful to them, mining the scientific literature, pulling this top-notch science, and then turning that science into accessible digital content for parents. That's been another great opportunity to help get science to parents. We're also actively working on a new project in the area of arthritis pain as well. Again, we think there's a lot of potential here, and certainly parents have been wonderfully receptive to this work and have really helped shape it.

RELIEF: So it's a model that worked for vaccination pain and now it's about expanding it to other areas.

Christine Chambers: Exactly.

RELIEF: In the last part of the podcast here, I just want us to switch gears a little bit to another important area of pediatric pain, and this is an area that you're also very interested in, which is this idea that if you experience pain early in life, in childhood, that

that will actually have consequences for the pain experience later in life. Can you describe that issue a little bit, and what the research says?

Christine Chambers: I think this is such a critical point that a lot of people don't understand. I still meet people who say, what's the big deal, it's just a needle, it'll be over soon, but increasingly, the research that's coming out, both from animal and human studies and all of the studies that have accumulated over the last 30 years, really strongly shows that there are long-term negative effects of poorly managed pain. Many of the original studies were done in the context of neonatal pain in the neonatal intensive care unit.

It's hard to believe, but as recent as the '70s and early '80s, people used to think that babies didn't feel pain or that it was too risky to use pain medications with them, and so babies often underwent very invasive procedures and surgeries like heart surgery with only paralytics. They weren't given anything for pain, and there were a couple of studies in the '80s and a mother who went public with her son's story in The Washington Post, that really drew attention to the fact that there are long-term effects of poorly managed pain.

In one study, babies who did not have appropriate analgesia or appropriate pain management were more likely to die from their surgery than babies who did receive proper anesthesia and pain management. Studies over the years have shown other long-term effects. We know that when pain is not managed, people take a longer time to heal. They're in a hospital longer. There have been long-term follow-up studies showing behavioral and emotional challenges in children who did not have proper pain management when they were younger.

In the newer area of brain imaging, studies have shown altered brain development as a result of poorly managed painful procedures early in life. Certainly, those are some of the physical effects around pain sensitization. Babies who've had lots of painful procedures tend to become more sensitive to pain. They don't toughen up, which is what a lot of people think. You'll become better able to cope if you have a lot of pain, and psychologically we know...I've worked with hundreds of kids and adults who have had needle phobias, and almost all of them can trace their fear back to one poorly managed painful procedure as a child.

The needle phobia literature is very interesting. People who are needle-phobic, they don't go to the doctor. They don't go for medical followup, and there's some evidence that people who are scared of needles even die sooner because of those fears. There clearly is a lot of reason to be concerned about children when it comes to pain, and we know that children who have chronic pain, two-thirds of them will go on to become adults with chronic pain.

I'm very interested in approaching the problem of pain from a developmental perspective. If we can do more to prevent and treat pain in childhood, potentially we can reduce a lot of associated burdens later in life.

RELIEF: Just to follow up on that, are there particular types of pain that children who had pain in childhood are most affected by, for instance, fibromyalgia or irritable bowel syndrome. Are there specific syndromes or pain conditions that [people] will be more likely to experience [later in life] if their pain wasn't managed well in childhood?

Christine Chambers: We've done studies just looking at what are the most common sources of pain in children, and we've also done some systematic review work looking at studies around the world. We know that the most commonly experienced type of chronic pain in children is headaches, followed by stomach aches, and the third most common is musculoskeletal or back pain. Those are the most common types of pain.

The few studies that have followed children who have chronic pain in adulthood are very interesting because they show that the children might not continue to experience the same type of pain that they had as a child, but that they're at increased risk of developing other types of pain problems. Again, that kind of points to the potential that some sort of pathway is being laid down in childhood that then makes an individual more vulnerable to developing different types of chronic pain later in life.

RELIEF: You mentioned this a little bit, what does the research then say about how to manage or treat chronic pain in childhood so that it doesn't have detrimental effects on pain later in life? One thing I'm thinking of is, to what extent should people look at biological treatment, so a medication versus a psychological treatment, for instance?

Christine Chambers: Fortunately, we do have a lot of empirically or evidence-based supported strategies to help, but they do tend to vary as a result of the type of pain. For example, for stomach aches, we know that medication, generally, for children who have your run-of-the-mill stomach aches that aren't associated with, say, a particular chronic disease like inflammatory bowel disease, for example, that medications are not effective. There have been studies and systematic reviews. Psychological interventions like cognitive behavior therapy and family support are much more effective.

On the other hand, [for] other types of pain like headaches, for example, pharmacological interventions play a very important role. For children who have complex chronic pain conditions where they are significantly disabled by their pain, interdisciplinary treatment teams, chronic pain teams, are very valuable. There might be a medical component, a pharmacological component. There is likely some sort of psychological involvement. There is often a physical therapist because just physical therapy and physical interventions we know are very helpful.

It really does vary. I think that the important message is that there are effective ways of treating pain in children, and that we need to do a better job of making sure that people are aware that there is help, and helping families to be able to access that support.

RELIEF: Great. Finally, I just want to ask you a last question. If you could just talk a little bit more about any studies that you're doing now and future studies that you might have planned in the area of pediatric pain.

Christine Chambers: Sure. We're continuing our work investigating the role of different family factors. We have just wrapped a really interesting study looking at the role of siblings in pain. Most of the work on families and pain has focused on parents, but obviously siblings play a big role in each other's lives, so we had a study where we had siblings come into our research lab and they each took part in an experimental pain task, and we studied how they interacted with each other and how their relationship impacted their pain.

We've also been really interested in studying children whose parents have chronic pain. So, we know when you have a parent who has chronic pain you're at increased risk, both genetically as well as from a social environment perspective, to develop pain yourself. We did a systematic review, looking at the areas in which these children might be struggling, and one of the studies running in my lab right now is trying to predict what factors contribute to risk and resilience in these children.

Our own preliminary observations are [that] these children are very, very much at risk and struggling, and really, in the adult chronic pain literature, there's very little targeted to adult chronic pain patients around how they can be helping their children who may end up developing chronic pain themselves.

Overall, I'm very interested in building on our work using social media, and studying and learning more about how parents can actually be a catalyst for improved pain management in hospital and by health professionals. There have been lots of attempts to try to improve pain management by targeting health professionals, but the data's pretty weak and there seems to be a lot more promise in empowering parents and having parents be able to influence the system and improve pain care for their kids.

RELIEF: There are some really exciting avenues for future research and really important questions to address, and so I think that's a great note to end on. Christine, thank you so much for being here today. It's been great to speak with you and to learn about all these different areas of children's pain, and one of the messages that I get, I think, is that it's just an area, children's pain, that should really be taken seriously. So we really look forward to following your research in this area in the future, so thank you so much.

Christine Chambers: Thank you for having me.