Kelly Coons: Supporting families of children with FASD

What you need to know

Through her Masters work looking at the experiences of families who are raising children with FASD, Kelly found that while families are able to adapt successfully, the main challenges that parents report are external to the family unit. The main challenge is that primary care professionals, teachers, and society in general don’t know and understand FASD. These findings sparked her current PhD research, examining the level of knowledge among medical, nursing, and midwifery students in Northern Ontario, in hopes of improving the level of understanding of FASD.

Kelly wants to learn how students’ interactions with society impact their beliefs about drinking during pregnancy and also to validate the feelings and concerns expressed by the families of children with FASD.

About Kelly

Born and raised in Markham, Ontario, Kelly moved to Sudbury to attend Laurentian University, where she received an Honours BA in Sport Psychology and an MA in Interdisciplinary Human Development. She is currently working on her PhD in Interdisciplinary Rural and Northern Health.

Kelly’s postgraduate work focused on families of children living with Fetal Alcohol Spectrum Disorder (FASD). She found her passion for this topic while working as a research assistant on part of the much larger project she is still currently working on at a much higher level.
Kelly has presented provincially, nationally, and internationally, and has numerous publications in the Journal of Intellectual and Developmental Disability and the Journal on Developmental Disabilities. She is also a conference committee member for the Research in Special Interest Group (RSIG) through the Ontario Association on Developmental Disabilities.

In her limited spare time, Kelly enjoys training for half marathons and playing dodgeball.

**What is Kelly’s research about?**

While working as an undergraduate student on a study examining the stress that parents experience when they have a child with autism or FASD, Kelly learned that parents of children with FASD were more stressed than the parents of children with autism. She also found that parents of children with FASD seemed to have less hope for the future. As a result, Kelly decided to take on an MA project focusing on the families of children with FASD.

**What did she do?**

Kelly interviewed 82 parents from 59 families across Ontario whose children ranged in age from one to 36 years. She included biological, adoptive, foster, and step parents, as well as grandparents, great-grandparents, and an aunt. She asked them to talk about their experiences raising a child with FASD to better understand the families’ strengths and challenges. She then analyzed their responses to look for themes using the Family Adjustment and Adaptation Response Model.

**What did Kelly find?**

Kelly found similarities among the different family

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*Patterson & Garwick, 1998; shown with permission*
types and locations across the province with regards to the challenges they face and what helps these families adapt to these challenges.

The challenges they reported are:

- FASD should not be a taboo topic - Professionals and society need to be better educated about FASD. Reducing the stigma of FASD and raising awareness about the effects of drinking during pregnancy are also important.

- Children with FASD need increased support – This includes meaningful employment, mentors/positive role models, assisted living, early diagnosis and early intervention, and safe and appropriate respite.

The five emerging themes for what has helped families to adapt include:

- Parental understanding of what FASD is and how to best help and advocate for their child.

- Day-to-day adaptation - “Every day is like the movie Groundhog Day” (i.e., creating a routine).

- The inner transformation of the parent – By facing these challenges they become better parents and better people.

- Informal supports – The support of a spouse/family/friends is invaluable.

- Formal supports – These families need to be connected to a support group and health professionals (e.g., doctors).

Parents recommend integrating firsthand and contextualized FASD education into the curriculum in universities, medical schools, and teacher’s colleges.

How can this research be used?

This research can be used to better support families of children with FASD and to help educate others and raise awareness of FASD and what it is like to be a parent of a child with FASD. The research also aims to help reduce stigma about the disability.

What’s next for Kelly?

Kelly is currently working on her PhD. There are mixed results in the literature around what primary care professionals know about FASD. There is little to no research on what nurse practitioners and midwives know. This is a concern because
health care providers are crucial in identifying women who are at risk of having a child with FASD. There are also other research findings that support the parents’ in Kelly’s study recommended to increase knowledge and understanding of FASD.

For her PhD project, Kelly plans to conduct a survey of students in medical, nursing, and midwifery programs. She will interview them about their knowledge of FAST and their perceived abilities in working with individuals with FASD and their families. She will also ask them to analyze case studies that she will develop based on data collected during her MA project. She plans to start work on this project in January 2015.

For more information contact Kelly Coons at kd_coons@laurentian.ca.

Publications:

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