

Disabilities and Coping During COVID-19 Pandemic: Summary Highlights

Experiences of Adults with 22q11.2 Deletion Syndrome in Canada and United States

September 26, 2020



This study was funded by:



Background

We wanted to understand how adults living with multiple disabilities associated with 22q11 Deletion Syndrome (“22q11.2DS” or simply “22q”), a microdeletion of the 22nd chromosome, were coping with the social distancing and other restrictions during the COVID-19 pandemic.

A broader goal was to explore and identify factors that could contribute to effective treatment and/or intervention in order to enhance the quality of life of those living with 22q11.2DS.

This was a rapid research project funded by Institute for Catastrophic Loss Reduction. The findings from this project will be further advanced by Jeremy Paulus, PhD Candidate at University of Waterloo, for his dissertation. Jeremy is also a parent of a child with 22q11.2DS.

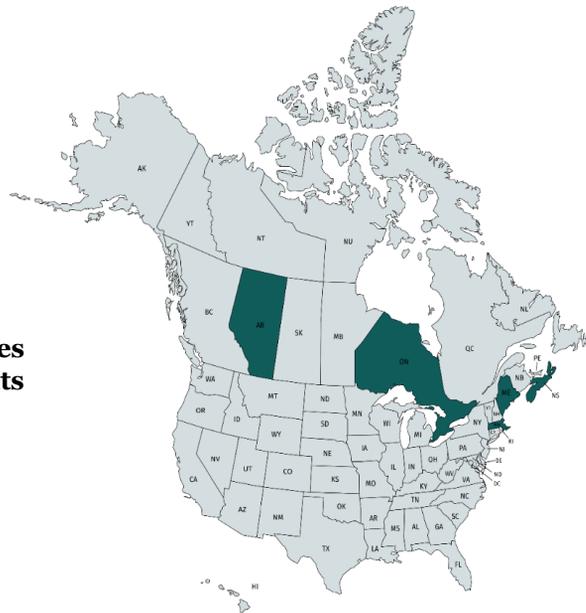
University of Waterloo’s Ethics Review Board approved the approach of all elements in this study.

Participants:

The Research Team worked with healthcare clinics and family networks in Canada and United States to promote and recruit participants (adults and parents of adults with 22q11.2DS) to interview.

Virtual interviews took place between May 12, 2020 and July 20, 2020. A total of 11 people were interviewed. Recordings were transcribed for future detailed analysis.

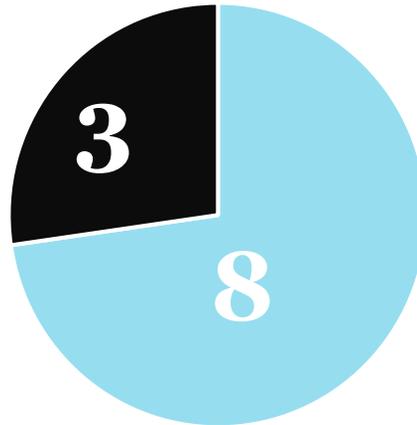
**Provinces and States
Where Participants
Reside**



Study Demographics

55%

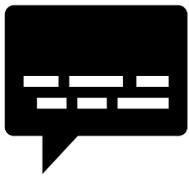
Between 18-24 yrs.



■ Female ■ Male

45%

Between 25-54 yrs.



Average of **3** Cognitive or Emotional Disabilities, Conditions, or Challenges Reported



Average of **5** Physical Health Disabilities, Conditions, or Challenges Reported



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Observations

Although difficulties did exist ...

We saw some evidence that adults with 22q11.2DS had some common challenges. This included struggling when hearing repetitive news stories about the pandemic. They expressed this as contributing to their anxiety but they all adapted and changed their behaviours by stopping or significantly limiting the news watching.

There were instances where their immune related deficiency prevented them from doing things in public. This was particularly challenging for participants who had very few close friends or were dating someone they could not see. This also limited their independence in being able to shop for themselves.

The lack of a driver's licence was a limiting factor for many. There were some frustrations with the inability to continue driving school which they required to get their licence. Concerns with the feeling of dependency from others because they could not drive and do things on their own was present. In contrast, the participants who had a licence shared how this provided means to do activities that seemed to help them cope (e.g. drive into the country to fish or drive to another city to volunteer or see friends).

Observations

... There were many more positive experiences

The overwhelming majority indicated that they were doing fairly well. Ten participants indicated that COVID-19 was not the most difficult situation they have had to deal with. Experiences that were more difficult than the COVID-19 pandemic included: having their parents raise their child, recovering from an alcohol dependency, not being able to manage finances effectively, difficulty dealing with palate and tastes, not always understanding what's happening around them, being abandoned by their mother, dealing with fears, and grieving the death of their grandmother.

There was evidence by several that the social distancing measures in place had little to no impact on them. In these cases the participants had their supports close. This usually included living with their parents or in one case in a group home.

All participants continued their treatment during the pandemic. This included taking medications, attending medical facilities where required or medical staff coming to their home (e.g. bloodwork). Participants also did virtual appointments though in some instances they felt a little uncomfortable using this technology.

Faith based support and/or engagement was evident in over half, or six, instances. This ranged from attending virtual church, attending synagogue earlier on, maintaining some contact with young adult group members virtually, and having conversations with their pastor on the phone.

Pets also played a role in many of the participants coping. In one instance their therapy cat passed away during the pandemic and this was very difficult to deal with. There were instances of how participants enjoyed taking their dogs for walks and spending time with them at home.

There was a passion for music in several cases as well. This included the passion for singing in choirs or attending musical performances. Listening to music was also comforting for many participants.

Themes Revealed



Using Social Media



Continuing Treatment Consistently



Driving Ability Matters



Engaging Close Friendships



Loving Parental Support



Interacting with Pets



Utilizing Faith Support

“

I WOULDN'T SAY IT'S BEEN DIFFICULT, BECAUSE I'M AN INTROVERT. SO, I APPRECIATE BEING HOME. SEEING THIS TIME BEING HOME AND STOPPING THE WORLD A LITTLE BIT, HAS ACTUALLY BEEN A GIFT FOR ME, SO... IT'S, IT'S BEEN GOOD.

”

- An Adult with 22q11.2DS

“

WITH HAVING 22Q ITS NOT REALLY THE MOST DIFFICULT TIME BUT IT IS ONE OF THE TOUGH TIMES.

”

- An Adult with 22q11.2DS

“

I'D SAY [MY SON/DAUGHTER] STEPPED UP TO THE PLATE... THE PANDEMIC HAS NOT REALLY AFFECTED HIM/HER.

”

- A Parent about their Adult Child with 22q11.2DS

Research Team

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Please contact Jeremy Paulus if interested to learn more about this study or associated 22q11.2DS research.



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