

Moms With Children Who Have Down Syndrome

Courtney Miller, Dr. Shera C. Thomas-Jackson, Dr. Gail E. Bentley,
Dr. Nicole Piland, Dr. Brianna S. Nelson Goff



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Human Development
& Family Sciences™

Parents with children who have Down Syndrome all have a different experience, both positive and negative.
Helps explain and process ambiguous loss.
Content analyses helps explore the qualitative answers.

Introduction

Although, there are many genetic-chromosome disorders, Down Syndrome takes the lead and is the most common one (as cited in Nelson Goff et al., 2013). Parents all over the world experience additional stress when raising a child who has Down Syndrome. Some parents have reported feelings of guilt, anger, and anxiety and have a negative experience (Skoto & Bedia, 2005). While others reported an experience that is much more positive and are full of joy (Kearney & Griffin, 2001; Marshak, 2015; Nelson Goff et al., 2013, O'Brien, 2007). In an effort to better understand the mothers in Nelson Goff's dataset and the cluster analysis of these mothers in Bentley et al. (2020), we look at how many times a participant mentions their faith, their overall attitude of having a child with DS, the types of support they reported, and if they had a positive or negative experience with the medical field.

Methods

All participants of this larger study (Nelson Goff et al., 2013) were asked to fill out a survey online, all with open ended qualitative questions and quantitative measures. The parents were asked to share a little bit about their experiences on what parenting a child who has down syndrome looks like by answering the survey questions. Some parents faced either a more positive or a more negative experience, sometimes even experienced both. To gain a better understanding of the qualitative data, we will be conducting a content analysis. Specifically, number of times faith is across all questions, a scaled score of attitude that some listed in the short answer response about current attitude of having a child with DS, positive vs. negative experiences reported in having a child with DS, types of support mentioned in the short answer responses, and if the medical experiences were positive or negative.

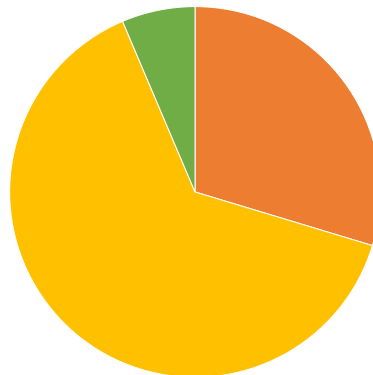
Medical Experience

Positive: 29.7%

Negative: 64%

Both positive and negative: 6.4%

Medical Experience Pie Chart



RESULTS

$N = 292$.

The more children in the family, the fewer negative experiences were reported with having a child with Down syndrome.

Mothers with less children were more likely to report more negative experiences, $r = -.131, p = .034$

Women who mentioned faith more ($n = 156, 1-11, \mu = 2.4, sd = 1.924$) often in the short answers reported more positive experiences. Positive experiences ($n = 276, 1-7, \mu = 2.75, sd = 1.382$) related to number of times faith is mentioned, $r = .166, p = .006$.

More than half experienced a negative interaction with doctors, nurses, hospital, etc. (see pie graph).

Contribution to Family Science

Better understanding of parental experiences with a child that has Down syndrome can inform family care providers and educators.



<https://www.shutterstock.com/search/down+syndrome+child>

Conclusion

This topic is important because in order to help parents with children who have down syndrome, we need to hear their input and their experiences. Medical staff can benefit by awareness on how many people have a negative experience compared to a positive one. This could enhance training on how to care and give the news that an infant has Down syndrome in a more positive way. This analysis allows for a deeper understanding on what life is like for mothers who have children with DS and what needs to be done to benefit them and their families.

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KANSAS STATE
UNIVERSITY

For questions about this poster: shera.Jackson@ttu.edu

For question about this data: bnelson@ksu.edu

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