



Understanding Paired Data of Parents of Children with DS: A Qualitative Directed Content Analysis

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Ambiguous Loss

Mom [104] We went through it very differently, which also added to the stress of the times. I was in it for a long time - months. I kept thinking about 'what ifs' and the future. My husband says he went very dark and deep very fast, but then came out of it in a couple weeks.

Dad [370] I ... went into anger and denial for a short period of time. [...] your hopes and dreams take a beating at first, until you realize all will be ok. For my wife people were sending condolence cards instead of congratulations and that paired with postpartum depression really took its toll.

Mom [175] The diagnosis was devastating. It was almost like experiencing a death, as the vision of who and what our son would be was clearly gone. In some ways I felt like it was worse than a death, though, because there was so much fear involved in not knowing what his life would be like ...

Dad [222] Initially I began to think of all the different things that [our son] would not be able to do or become.

Purpose of the Study

Previous studies have demonstrated a sense of ambiguous loss (AL) among fathers of children with Down syndrome (DS) (Bentley, 2011; Bentley, Zvonkovic, McCarty, and Springer, 2015). Living with ambiguity is difficult for some people and raising any child is filled with ambiguity, however that ambiguity is tempered by "typical" expectations. Raising a child with a development disability has greater ambiguity as parents wonder what the extent of the "disability" will be for their child.

The goal of this study is to gain a deeper understanding of couples raising a child with DS. To do this we will look at the paired data of 16 couples who responded to a nationwide data collection through DS organizations. Several studies have looked at this data*, however none of them have examined the paired data of the 16 couples that are identified.

A directed content analysis of open ended questions could provide insight as to the meaning making these parents employed to address their specific lived experiences as parents of a child with DS as they addressed situations of psychological presence/physical absence or psychological absence/physical presence as outlined by Ambiguous Loss (Boss, 1993, 1999, 2007; Hsieh & Shannon, 2005). The agreement, or lack thereof, between parents could have a significant impact on their coping styles and family wellbeing.

Abstract

The theory of Ambiguous loss provided guidance for a qualitative directed content analysis of the responses of 16 couples to open ended questions about their experiences as parents of children with Down syndrome (DS) (Boss, 1993, 1998, 2007; Hsieh & Shannon, 2005). Three types of coping with ambiguous loss have been found previously. Mastering, Connecting, and Thriving were seen in the father's responses. The goal of this study is to see if those three types of coping are also reflected within the couple dyad.

Ambiguous Loss Theory (AL)

An ambiguous loss is a perceived stressor situation that is expected to change over time (Boss, 2007). Looking for evidence of an ambiguous loss in parents' responses to open ended questions is to look for evidence of ambiguity. For some parents this is seen in their descriptions of the psychological presence of the typical child they expected but was not born. It can also be seen when parents describe the child who was born with DS that does not fulfill their psychological expectation of a typical child. In both these scenarios can be found the perceived stressful situation of ambiguous loss, along with the expectation that it will change. When discussing the birth and life of a child with DS the ambiguity lies in the uncertainty of functionality of the child. Although individuals with DS may be able to live close to a typical life, there is an increased level of ambiguity about what their most likely level of functioning may be.

Methods

A qualitative directed content analysis begins with theoretical or other research findings guiding the initial efforts to find themes in the text data (Hsieh & Shannon, 2005). The guidance for this analysis comes from the Theory of Ambiguous Loss (Boss, 1993, 1999, 2007). Previous research has shown that the father's responses to these questions revealed themes of ambiguous loss as well as three different types of effort to cope with the ambiguous loss (Bentley, 2011; Bentley, Zvonkovic, McCarty, and Springer, 2015).

Resilience by Connecting

Mom [411] I volunteer for the Down syndrome Association, attend conferences and read and research anything I can find about [DS].

Dad [412] It has really made me slow down and smell the roses so to speak.

Results

The theory of Ambiguous Loss (AL) is both a family theory for research as well as a therapeutic theory for treatment. Any treatment technique has a goal and the goal of the theory of AL is to help clients attain a point of resilience. In the responses of these couples the perceived ambiguous stressor is seen as well as the development of resilience. Resilience is a strong descriptor of the husbands in this study (Bentley, 2011; Bentley, Zvonkovic, McCarty, and Springer, 2015). In this examination of couples the wives reflect that same sense of resilience. Their resilience is seen in the coping styles originally described in the fathers which fit expectations Boss describes in her work (Boss, 1993, 1999, 2007).

Conclusion

- The three coping styles identified in the previous study continued to hold as the couples data were examined.
- The majority of couples appeared to be connected in their responses to the questions. Relationship skills can contribute to parenting skills.
- The coping strategies adopted by parents are often related to the resources available to those parents, thus providing parents with information about ambiguous loss when they first learn of a DS diagnosis could be helpful.
- Coping behaviors reflect skills, and effective coping skills can be learned.

Ambiguous Loss with Resilience

Mom [488] I have been more terrified about how others will react towards him. I have always been a shy person with few friends, and so I think for me it has been more of what will people think or say. But now that I have him home [...] I am happy that God would choose to bless us with a special child. I had several people tell me what better parent could a child like him have. I am humbled by their kind words.

Dad [487] Just the realizations that what we had planned for our futures, even though they were vague at best, were now shot. I think everyone going into marriage and parenting with a couple of ideas in their head. You get married, at some point you have kids. You raise your kids, send them to school, then to college, and at some point they leave the nest and make one of their own. In having a Downs child I have come to a realization (a difficult one at that) that this might not be the case for us. With not knowing the severity that the Downs will effect him both physically and mentally, our plans for the future have been shot to pieces. Who knows if he will ever be able to live by himself ... want to get married, or even be able to find someone to love him for what he is, a person with Downs ... Knowing all of this it's just hard to be able to plan for the future in 20 years. I had a general idea, ... but even that vague of an idea is gone. [...] I have complete faith in God to work this out one way or the other, and he will not give us more than we can handle.

Resilience through Mastery

Mom [354] We are thrilled with every new think he learns and both get a little nervous when there are falls in his progress.

Dad [323] I am more of a 'drill sergeant' to encourage my daughter to fulfill her maximum potential.

Resilience by Thriving

Mom [175] We share the same fundamental view that God made [our son] for a reason and that our son is not a genetic mistake. Because of that, we have learned to really enjoy him.

Dad [222] ... we both believe that God has ... plans for [our son] to prosper and plans for him to have hope and a future (Jeremiah 29:11).

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Presented: National Council on Family Relations, Baltimore, MD November 2019

* See back of handout for citations and demographic information for this study.

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* (Bentley, 2011; Bentley, Zvonkovic, McCarty, and Springer, 2015; Cless, Nelson Goff, & Durtschi, 2018; Farkas, Cless, Cless, Nelson Goff, Bodine, & Schmelzle, 2019; Krueger, Cless, Dyster, Reves, Steele, & Nelson Goff, in press; Nelson Goff, Monk, Staats, Malone, Tanner, & Springer, 2016; Staats, Nelson Goff, Springer, & Monk, 2015; Nelson Goff, Springer, Foote, Frantz, Peak, Tracy, Veh, Bentley, & Cross, 2013)

Table 1: Demographic information about participants

All couple participants reported to be of European American descent, with income over 40K with eight couples reporting over 100K a year, married from 5-20 years ($M = 11.22$, $SD = 4.56$) with the majority (75%) in their first marriage, ages ranging from 30-53 ($M = 38.81$, $SD = 5.70$), with over half reporting education beyond a Bachelor's degree. For the sixteen couples in this study, 75% had a male child with Down syndrome and half of the couples had the child with Down syndrome in the previous two years. The children with Down syndrome ranged in age from one month to eleven years ($M = 3.83$, $SD = 2.90$).

	N (%)
Employment	
Full-Time	22 (68.8)
Part-Time	4 (12.5)
Not currently employed	2 (6.3)
Stay-at-home Parent	3 (9.3)
Religion	
Protestant	11 (34.4)
Catholic	1 (3.1)
Jewish	6 (18.8)
None	7 (21.9)
Education	
High School Diploma/GED	1 (3.1)
Some College	4 (12.5)
Bachelor's Degree	8 (25)
Some Graduate	4 (12.5)