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Parents of Children with Down Syndrome: A Comparison of Prenatal and Postnatal Diagnosis Groups

Authors

Natira Staats,[1]
Briana S. Nelson Goff,[1*]
Nicole Springer,[2*]
J. Kale Monk[3]

[1] School of Family Studies and Human Services, Kansas State University, Manhattan, KS

[2] Department of Community, Family, and Addiction Sciences, Texas Tech University, Lubbock, TX

[3] Department of Human and Community Development, University of Illinois at Urbana-Champaign, Urbana IL, USA

[*] Denotes equal contribution as 2nd authors

Correspondence

bnelson@k-state.edu.

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Abstract

The present study explored current intrapersonal and interpersonal functioning of parents with a child diagnosed with Down syndrome. The participants included a national sample of participants who learned of their child's diagnosis either from prenatal screening/testing (n = 285) or from a postnatal diagnosis (n = 159). The main focus of this study included parents' coping strategies, hope, life satisfaction, relationship adjustment, and relationship satisfaction. These variables were explored using an Analysis of Variance (ANOVA) design. Similar to qualitative findings of limited differences between timing of awareness in diagnosis, the results indicated no statistically significant differences between the two groups on the measures of interest. Based on these findings, we provide initial quantitative evidence that parents who receive a postnatal diagnosis may not be at a large disadvantage compared to parents who had more time to prepare for a child with a Down syndrome diagnosis. The study provides an initial quantitative analysis of parents' levels of functioning related to their child's Down syndrome diagnosis based on the timing of the diagnosis, which is currently absent in the literature.

While some research describes parental reactions and experiences upon receiving a prenatal genetic diagnosis (Allen & Mulhauser, 1995; Balkan, Kalkanli, Akbas, Yalinkaya, Alp, & Budak, 2010; Chaplin, Schweitzer, & Perkoulidis, 2005; McKechnie & Pridham, 2012), fewer studies have explored the experience of receiving a postnatal diagnosis. This is particularly critical since the majority of parents find out about their baby's condition after the child is born (Skotko, 2005a). Mothers of children with Down syndrome (DS) often find the delivery of the diagnosis offensive as it is rarely delivered in conjunction with discussion of the positive aspects of DS, and parents feel they are not given adequate resources (Skotko, 2005b; Skotko, 2005c). Following the delivery of the diagnosis, mothers have reported feeling anxiety, anger, and guilt (Skotko & Bedia, 2005). Skotko, Kishnani, and Capone (2009) suggest that the initial diagnosis be provided by a professional who has training and is knowledgeable about Down syndrome. Meetings should be in-person, in a private setting, include both partners present if possible, and should convey current and accurate information on medical issues, support groups, and other resources (Nelson Goff et al., 2013; Skotko et al., 2009; Skotko, Capone, & Kishnani, 2009; Skotko, Levine, & Goldstein, 2011a).

A similar focus was used to explore the impact of prenatal versus postnatal diagnosis on the psychological distress in

parents of children with severe congenital heart disease (Brosig, Whitstone, Frommelt, Frisbee, & Leuthner, 2007). They found that both groups reported greater psychological distress levels than the norm at the time of diagnosis; however, the two groups did not differ significantly from each other. At six months after birth, the postnatal group scores were similar to the norm, but the prenatal group still scored considerably higher in terms of psychological distress (Brosig et al., 2007). In a qualitative study of prenatal and postnatal parent groups, Nelson Goff et al., (2013) found that both groups reported similar experiences and reactions, regardless of the timing of the DS diagnosis. However, currently there is limited research exploring the experiences of parents who received a postnatal diagnosis, particularly quantitative or comparison studies. The present study was conducted to provide a direct evaluation of parents' coping strategies, hope, life satisfaction, relationship adjustment, and relationship satisfaction in a sample of parents of children with Down syndrome based on the timing of the diagnosis (prenatal vs. postnatal). Current literature on each of these areas of intrapersonal and interpersonal functioning will be reviewed next.

Coping Strategies

Families who utilize positive coping strategies and demonstrate adjustment or resilience better adapt to the stressors involved in raising a child with a disability (Cunningham, 1996; Joosa & Berthelsen, 2006; King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009; Twoy, Connolly, & Novak, 2007). Many of the studies that addressed prenatal testing and counseling were concerned with the emotions and experience that accompany the diagnosis and how parents cope with the news (Allen & Mulhauser, 1995; Cederholm, Sjödén, & Axelsson, 2001). The experience of receiving a prenatal diagnosis often varies among parents, but many report encountering an array of emotions, including stress, disbelief, sadness, anger, and confusion (Nelson Goff et al., 2013). It is typical for studies to implicate mainly negative experiences of the diagnosis process, but some studies have addressed the positive outcomes that can occur from prenatal testing (Statham & Green, 1993; Watson, Hayes, & Radford-Paz, 2011). In addition to the specific coping strategies parents use, two potential positive outcomes, hope and life satisfaction, are described next.

Hope

Hope has been defined by three factors: temporality and future (cognitive-temporal dimension), positive readiness and expectancy (affective-behavioral dimension), and interconnectedness (affiliative-contextual dimension) (Herth, 1992). In 2003, Kausar, Jevne, and Sobsey conducted interviews to evaluate hope in families of children with disabilities. They found that hope is a positive, changing transformative process that helps parents reframe their lives. Parents reported that their lives were enriched with empathy, a hope, love, care, compassion, and value, as a result of their experience of having a child with a disability. Parents also often report undergoing positive personal growth, which they credit to parenting a child with a disability (Kausar et al., 2003).

Life Satisfaction

Until recently, the quality of life of parents of children with disabilities has been an overlooked area of research even though belief systems of families are identified as one of the most important factors affecting adaptation and resilience in families (Brown, Anand, Fung, Isaacs, & Baum, 2003; King, Zwaigenbaum, King, Baxter, Rosenbaum, & Bates, 2006). Parenting a child with a disability can force a reexamination of belief systems for parents. Through their personal values, priorities, and world views, parents can gain a sense of control and understanding by employing different strategies for thinking about their role as a parent, the role of the family, and their child in general (King et al., 2006). These areas of intrapersonal functioning have important implications on how people cope in relationships. In fact, marital relationships have been identified as a critical component of parental coping, and more specifically parent well-being (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006).

When considering other relationships, siblings of children with Down syndrome have expressed love and pride for their sibling without relation to functional skills, health conditions, or educational challenges (Skotko,

Levine, & Goldstein, 2011b). When asked what advice they would give to new parents of children with Down syndrome, people with Down syndrome have expressed that their lives are good (Skotko, Levine, & Goldstein, 2011c). These individuals also emphasized that there will be a mutual love between parents and their child with Down syndrome, and that parents should encourage and treat their child with DS like they would treat any other child (Skotko et al., 2011c).

Relationship Adjustment and Satisfaction

Researchers have examined the role of the partner relationship in adjusting to a prenatal diagnosis (Humphreys, Cappelli, Aronovitch, Allanson, & Hunter, 2008). Parents tend to rely heavily on their partners for support (Chaplin et al., 2005). In fact, five relationship variables have been described for women's adjustment following prenatal testing and counseling: partner agreement, anticipated joint decision-making, perceived partner support, empathic responding, and partner support seeking (Humphreys et al., 2008). These five factors have been found to be most important in promoting individual and marital adjustment following a prenatal diagnostic testing experience (Humphreys et al., 2008).

While the overall impact of parenting a child with a disability can be stressful and potentially negative, the impact is not as severe as what is often assumed (Risdal & Singer, 2004). In reality, parent and family problems in families of children with Down syndrome have been shown to be lower than families of children with other disabilities (Fidler, Hodapp, & Dykens, 2000). Urbano and Hodapp (2007) found that parents of children with Down syndrome had a lower overall rate of divorce than parents of children with other disabilities or parents of children who did not have a disability. Further, they showed that younger age and less education were factors that increased the likelihood of divorce in parents of children with Down syndrome (Urbano & Hodapp, 2007). When divorce did occur, it was most likely to occur within the first two years following having a child with Down syndrome (Urbano & Hodapp, 2007). It has also been suggested that there are few differences in family and marital functioning when comparing families of children with DS to families of children without disabilities, but many of these studies have mixed results (see Hartley, Seltzer, Barker, & Greenberg, 2011; Van Riper, Ryff, & Pridham, 1992). Thus, additional research that addresses these variables is needed.

Purpose of the Current Study

The current literature addressing the intrapersonal and interpersonal functioning of parents of children with developmental disabilities, specifically Down syndrome, is limited. Much of the research has been qualitative in nature (Joosa & Berthelsen, 2006; Kausar et al., 2003; King et al., 2009; McKechnie & Pridham, 2012), and most studies do not address level of functioning in parents, particularly intrapersonal and interpersonal variables. In addition, much of this research has included either prenatal or postnatal participants, without comparing the unique experiences of these groups of parents, whose diagnostic experiences and outcomes may or may not be similar. Few recent studies comparing these two groups currently exist.

Based on the limited research comparing prenatal and postnatal groups of parents of children diagnosed with Down syndrome, we sought to address five areas of functioning: coping strategies, hope, life satisfaction, relationship adjustment, and relationship satisfaction. These areas were selected to include both individual functioning variables as well as areas of relationship functioning to understand whether, based on participant self-report, there were any differences between the groups across these domains. Because no other empirical research has compared these variables in a sample of parents of children with Down syndrome, we utilized the following null hypothesis in the research:

There will be no differences in coping strategies, hope, life satisfaction, relationship adjustment, or relationship satisfaction in the prenatal diagnosis group of parents compared to the postnatal diagnosis group of parents.

Materials and Methods

Procedure

This study was part of a larger study that explored the experiences of parents in families with a child with Down syndrome. Participants in the larger study were recruited through several local and national Down syndrome groups, including the National Down Syndrome Congress (NDSC; ndsccenter.org; research webpage, national newsletter, and at one national convention), Down Syndrome Guild of Greater Kansas City (kcdsg.org; webpage and newsletter), Band of Angels (bandofangels.com), and the Council for Exceptional Children (cec.sped.org). In addition, the NDSC forwarded information to contacts at each of their affiliate organizations nationwide, who then distributed the study information through their local membership listservs. The research procedure was approved by the Kansas State University and Texas Tech University Institutional Review Boards (IRBs). Recruitment materials included information about the study and the survey weblink for interested participants to access and complete online. All recruitment and research materials were written in English, and the survey was only available online (participants were provided with the option to contact the PIs for a paper copy, but no requests were received). Although the survey remained open for further data collection, at the time data analysis was conducted for the current study, participants from two countries, including 22 states in the United States had completed the online survey.

Measures

Coping strategies. The Family Crisis Oriented Personal Evaluation Scales (F-COPES; McCubbin, Olson, & Larsen, 1991) is a 30-item, five-subscale measure used to quantify coping strategies employed by families facing challenging situations. Items are scored using a 5-point Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*); sample items include: *sharing our difficulties with relatives, showing that we are strong,* and *accepting that difficulties occur unexpectedly*. Scores range from 30 to 150, with higher scores indicating higher levels of coping. The reliability of F-COPES is shown to have high internal consistency (a = 0.86), good factorial and concurrent validity, and correlates with other family measures (McCubbin et al., 1991). Cronbach's alpha in the current study was 0.52.

Hope. The Herth Hope Index (HHI; Herth, 1992) is a 12-item scale adapted from the Herth Hope Scale (HHS). Items are scored on a 4-point Likert scale from 1 (*strongly disagree*) to 4 (*strongly agree*); sample items include: *I have a positive outlook toward life, I feel all alone* (reverse scored), and *I have a sense of direction*. Scores range from 12 to 48, with higher scores indicating higher levels of hope. Internal consistency of the HHI is good (a = 0.97), as is test-retest reliability (0.91;,Herth, 1992). Cronbach's alpha in the current study was 0.88.

Life satisfaction. The Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985) is a 5-item scale used to assess subjective, general life satisfaction. This scale uses the subject's own assessment of his or her quality of life. Items are scored on a 7-point Likert scale from 1 (*strongly disagree*) to 7 (*strongly agree*); sample items include: *In most ways my life is close to my ideal,* and *The conditions of my life are excellent*. Scores range from 5 to 35, with higher scores indicating greater satisfaction with life. Internal consistency is good (a = 0.87). Test-retest reliability appears to be good, with a correlation of 0.82; and concurrent validity has been shown to correlate with nine other measures of life satisfaction (Diener et al., 1985). Cronbach's alpha in the current study was 0.89.

Relationship adjustment. The Revised Dyadic Adjustment Scale (RDAS; Busby, Christensen, Crane, & Larson, 1995) is a 14-item, three subscale measure used to assess relationship adjustment. Items are scored on a 6-point Likert scale; scores range from 0 to 69, with higher scores indicating higher relationship satisfaction. Sample items include: *How often do you and your partner quarrel, Do you and your partner engage in outside interests together,* and *How often do you and your partner work together on a project*? Distressed and nondistressed samples can be reliably differentiated using this scale. Internal consistency is good with a = 0.90 (Busby et al., 1995). Cronbach's alpha in the current study was 0.87.

Relationship satisfaction. The Couples Satisfaction Index (CSI; Funk & Rogge, 2007) is a scale that

measures relationship satisfaction; in the current study, the 4-item version was used. Scores on the 4-item version of the CSI range from 0 to 21, with higher scores indicating higher relationship satisfaction. Sample items include: *I have a warm and comfortable relationship with my partner,* and *How rewarding is your relationship with your partner*? Convergent validity for the CSI is strong, and it demonstrates good construct validity and internal consistency (a = 0.94 for 4-item version; Funk & Rogge, 2007). Cronbach's alpha in the current study was 0.91.

Results

Participants were identified in either the "prenatal diagnosis group" or "postnatal diagnosis group" based on their response to the following question: *How did you learn of your child's diagnosis*: (a) after birth through a chromosome/blood test, (b) early ultrasound markers during pregnancy, (c) amniocentesis results during pregnancy, (d) CVS biopsy during pregnancy, or (e) Other (specify). Participants were identified in the "postnatal diagnosis group" if they selected the "a" response; participants were identified in the "prenatal diagnosis group" if they selected the "b", "c", or "d" response. Participants who selected the "Other" response were placed in one of the two groups based on their text description; responses that could not be identified as prenatal or postnatal (e.g., "the doctor told us") were omitted from analysis. Out of 644 total survey responders, there were missing or matched partner data for 200 cases, resulting in 444 usable independent cases for data analysis: 64.2% (*n* = 285) of participants were in the prenatal diagnosis group, and 35.8% (*n* = 159) of participants were in the postnatal diagnosis group. In general, participants were predominantly White females, 35–54 years of age, who were currently in their first marriage. There were no statistically significant group differences on demographics between the prenatal and postnatal diagnosis groups (for additional demographic data, see Table 1).

Table 1. Demographic Statistics for Prenatal and Postnatal Diagnosis Groups

Variables	*Prenatal Group (n = 285)*	*Postnatal Group (n = 159)*
Gender of Parent		
Male	14.4% (*n* = 41)	14.5% (*n* = 23)
Female	85.6% (*n* = 244)	84.3% (*n* = 134)
Age of Parent		
Under 34	25.0% (*n* = 71)	16.4% (*n* = 26)
35–44	43.7% (*n* = 124)	44.0% (*n* = 70)
45–54	21.5% (*n* = 61)	29.6% (*n* = 47)
55 and Older	9.9% (*n* = 28)	10.1% (*n* = 16)
Race/Ethnicity		
White	90.8% (*n* = 256)	91.2% (*n* = 145)
Black/African American	0.0% (*n* = 0)	2.5% (*n* = 4)
American Indian/Alaska Native	0.4% (*n* = 1)	1.3% (*n* = 2)
Asian/Pacific Islander	1.1% (*n* = 3)	0.0% (*n* = 0)
Other	2.5% (*n* = 7)	2.5% (*n* = 4)
Hispanic/Latino	5.3% (*n* = 15)	2.5% (*n* = 4)
Religion		
Protestant	56.9% (*n* = 160)	60.8% (*n* = 96)
Catholic	25.3% (*n* = 71)	23.4% (*n* = 37)
Jewish	3.9% (*n* = 11)	4.4% (*n* = 7)
Other	2.9% (*n* = 8)	3.2% (*n* = 5)
None	11.0% (*n* = 31)	8.2% (*n* = 13)

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Table 1. Demographic Statistics for Prenatal and Postnatal Diagnosis Groups (continued)

Education				
Some graduate work	37.5%	(*n* = 106)	38.4%	(*n* = 61)
Completed college	37.8%	(*n* = 107)	32.1%	(*n* = 51)
Some college	18.4%	(*n* = 52)	25.2%	(*n* = 40)
High school degree or less	6.3%	(*n* = 18)	4.4%	(*n* = 7)
Employment				
Full-time	47.7%	(*n* = 136)	38.4%	(*n* = 61)
Part-time	11.0%	(*n* = 49)	17.0%	(*n* = 27)
Homemaker	24.2%	(*n* = 69)	20.8%	(*n* = 33)
Other	9.5%	(*n* = 27)	17.0%	(*n* = 27)
Household/Family Income				
< $50,000	19.4%	(*n* = 54)	23.8%	(*n* = 36)
$50,000–99,999	41.7%	(*n* = 116)	36.4%	(*n* = 55)
> $100,000	38.8%	(*n* = 108)	39.7%	(*n* = 60)
Relationship Status				
Married	87.2%	(*n* = 246)	82.9%	(*n* = 131)
Dating	1.4%	(*n* = 4)	1.9%	(*n* = 3)
Engaged	0.7%	(*n* = 2)	2.5%	(*n* = 4)
Separated	1.4%	(*n* = 4)	0.0%	(*n* = 0)
Divorced	4.3%	(*n* = 12)	6.3%	(*n* = 10)
Remarried	0.4%	(*n* = 1)	0.6%	(*n* = 1)
Living Together	2.5%	(*n* = 7)	1.9%	(*n* = 3)
Single	1.4%	(*n* = 4)	1.9%	(*n* = 3)
Other	0.7%	(*n* = 2)	1.9%	(*n* = 3)
Total Number of Marriages				
None	3.2%	(*n* = 9)	4.5%	(*n* = 7)
1	79.0%	(*n* = 222)	72.6%	(*n* = 114)
2	13.9%	(*n* = 39)	19.1%	(*n* = 30)
3 or >	4.0%	(*n* = 11)	3.8%	(*n* = 6)
Time in Current Relationship				
< 5 years	8.2%	(*n* = 22)	8.7%	(*n* = 13)
5–10 years	35.1%	(*n* = 94)	26.2%	(*n* = 39)
11–20 years	35.4%	(*n* = 95)	47.7%	(*n* = 71)
> 20 years	21.3%	(*n* = 57)	17.4%	(*n* = 26)
Number of Children with DS				
1	98.6%	(*n* = 278)	96.2%	(*n* = 150)
2	1.1%	(*n* = 3)	3.2%	(*n* = 5)
Age of Child with DS				
< 4	42.7%	(*n* = 120)	39.5%	(*n* = 62)
4–10	32.0%	(*n* = 90)	33.8%	(*n* = 53)
11–24	19.6%	(*n* = 55)	21.0%	(*n* = 33)
25 or Older	5.7%	(*n* = 16)	5.7%	(*n* = 9)
Gender of Child with DS				
Female	44.6%	(*n* = 127)	47.8%	(*n* = 76)
Male	53.7%	(*n* = 153)	50.9%	(*n* = 81)

To test our hypothesis, the five variables were analyzed using ANOVA data analyses to determine differences between the two diagnosis groups (see Table 2 for results and correlation data). Significant correlations were found between all variables except for coping (F-COPES) and relationship adjustment (RDAS) scores. Results of the ANOVA revealed no statistically significant differences between the two groups on the five variables: coping (F-COPES; F [1,320] = 2.79, $p > .05$), hope (HHI; F [1,318] = 0.01, $p > .05$), satisfaction with life (SWLS; F [1,318] = 0.81, $p > .05$), relationship adjustment (RDAS; F [1,298] = 0.38 $p > .05$), or relationship satisfaction (CSI; F [1,296] = 0.12, $p > .05$). Thus, our hypothesis that there would be no statistically significant differences between prenatal and postnatal groups for all variables of interest was confirmed.

Discussion

The current study sought to explore coping strategies, hope, life satisfaction, relationship adjustment, and relationship satisfaction among parents of children with a diagnosis of Down syndrome. A national sample of parents participated in the online survey and data were analyzed to determine whether differences were evident according to timing of diagnosis (prenatal or postnatal). While there is some literature that addresses these areas in parents of children with developmental disabilities, we found little research specifically comparing prenatal and postnatal groups. In the present study, no significant differences were identified between the prenatal and postnatal groups in any of the areas examined. Findings therefore suggest that these two groups are similar in their coping strategies, sense of hope, life satisfaction, relationship adjustment, and relationship satisfaction. The primary difference between the two groups of parents was the timing of when they learned of the Down syndrome diagnosis. This is similar to findings in from a study of parents of children with diagnosed heart conditions (Brosig et al., 2007).

While the specific data in this study did not result in statistically significant differences between these two groups of parents, results provide an initial empirical understanding of several important parent variables. Parents of children with a disability appear to employ a variety of coping strategies to adjust to the range of reactions and stressors they face (Joosa & Berthelson, 2006; King et al., 2009; Twoy, Connolly, & Novak, 2007). Similarly, parents

Table 2. Analysis of Variance and Correlational Results for Prenatal and Postnatal Diagnosis Groups

	Prenatal	*Postnatal*								
Variables	*M (SD)*	*M (SD)*	*F*	*p*	*NSM*	*DCS*	*1*	*2*	*3*	*4*
1. F-COPES	104.85 (15.57)	103.96 (16.76)	2.79	.10	93.3	n/a	—			
2. HHI	42.05 (5.04)	41.79 (4.95)	.01	.91	32.4	n/a	.41***	—		
3. SWLS	26.69 (6.01)	26.63 (6.50)	.81	.37	23.5[a]/ 25.8[b]	n/a	.28***	.59***	—	
4. RDAS	47.57 (9.03)	47.16 (10.14)	.38	.53	48	42	.05	.28***	.42***	—
5. CSI	15.32 (4.50)	15.00 (5.06)	.12	.73	16	13.5	.11*	.36***	.57***	.68***

Note. F-COPES = Family Crisis Oriented Personal Evaluation Scales (McCubbin et al., 1991); HHI = Herth Hope Index (Herth, 1992); SWLS = Satisfaction with Life Scale (Diener et al., 1985); RDAS = Revised Dyadic Adjustment Scale (Busby et al., 1995); CSI = Couple Satisfaction Index (Funk & Rogge, 2007); NSM = normed scale mean; DCS = distressed cut score (if available).

[a] Undergraduate students. [b] Older adult population.

**p < .05 **p < .01 ***p < .001, two-tailed.*

navigate this journey through support systems and personal values and beliefs, often gaining hope and reaching positive outcomes (Kausar et al., 2003). In addition, consistent with the literature on marital relationships among parents of children with developmental disabilities (Van Riper et al., 1992), our participants did not report impaired relationship satisfaction in either group, nor were there differences between the groups. Thus, unlike the Brosig et al. (2007) study, which found higher impairment in the prenatal versus postnatal group at follow-up, our study found no significant differences across multiple measures between the two groups. In addition, comparisons to normed data on each of the measures indicated that our participants were comparable to or above the normed means (See Table 2). We specifically assessed a wide range of areas, including intrapersonal and interpersonal functioning variables, which allowed for a broad assessment to understand whether these groups might be similar or different, adding to the current literature by contributing a quantitative analysis of these two parent groups. Thus, while our hypothesis was supported, our results also provide points of comparison for future research on parents of children with special needs.

Study Limitations, Future Research and Practice Implications

The current research provided information on several variables among parents who either received a prenatal or postnatal diagnosis of Down syndrome for their child. The study represented participants from across the United States, including both male and female participants; however, participants were predominantly White, married females who reported a high socioeconomic status. Participants were also reporting their experiences retrospectively, mostly several years after the diagnosis, so it is important to recognize that these results may differ if parents were assessed immediately after receiving the diagnosis. However, Skotko (2005a) describe the preliminary experience of parents when they receive their child's special needs diagnosis as a "flashbulb memory," one that parents do not forget and is etched in their memories forever. Nelson Goff et al. (2013) found similar results; while some parents' experiences were years earlier, their descriptions of that first experience of learning about their child's diagnosis was as clear as if it had just happened, their descriptions were laden with emotions and very specific details of their memories of that moment. More specifically, participants described the overwhelming emotions, including grief, loss, mourning, guilt, and anger, that they experienced in ways that resembled a flashbulb memory. Other research has described that parents report similar experiences at the news of their child's diagnosis (Joosa & Berthelsen, 2006; Poehlmann, Clements, Abbeduto, & Farsad, 2005). Thus, while it should be noted that much of the current literature on the experiences of parents upon first learning of their child's Down syndrome diagnosis is retrospective in nature, parents' memories of that experience seem to remain quite vivid and clear. Further research may consider addressing differences in parents' reports immediately after the diagnosis to determine if there are any differences between prenatal and postnatal groups at that time, as well as further longitudinal research on differences across the lifespan (Nelson Goff, Monk, Staats, Malone, Tanner, & Springer, in review). Finally, the presence of "complex needs" in this sample of children with Down syndrome was not assessed in the current study, so the impact of more severe impairment or multiple diagnoses (e.g., Autism Spectrum Disorder and Down syndrome, severe medical or behavioral issues) remains unknown.

This study was further limited by selection bias. A population-based registry was not used to obtain participants. An online, open convenience sample was used to inform this study and, as a result, findings may not be representative of all families of children with Down syndrome. Additionally, it is possible that parents who had extreme experiences may have been more likely to participate. Because of this, it is not possible to generalize the current results to all parents of children with Down syndrome. The significance of the non-responder effect is not clear at this point due to the inability to calculate a response rate.

It is important to explore the experiences of parents who received a positive Down syndrome or similar prenatal diagnosis, and who chose to continue the pregnancy. Pregnancy

termination and continuation due to a prenatal diagnosis may be influenced by many factors, and parents who choose not to terminate their pregnancy are a unique group of individuals whose experiences require further exploration. In addition to the limitations noted previously, further research is needed to explore the experiences of fathers of children with Down syndrome (Bentley, 2011), as well as more diverse and representative populations (Cuskelly, Hauser-Cram, & Van Riper, 2009; Hodapp, 2007). Although we directly recruited participants in person at an NDSC conference, including specifically attending father and Latino/a special interest groups, the numbers of these participants remained low in our sample.

The current results also provided several implications for working with parents of children with Down syndrome and other special needs. Regardless of the timing of the diagnosis, parents need to be engaged in accessing a support network to navigate this journey (Nelson Goff et al., 2013). These early contacts may be particularly important for new parents to obtain resources specific to Down syndrome and other developmental disabilities in their local community, such as parent support groups, or other national resources providing information and support (e.g., NDSC, NDSS, online resources).

Parents who learn of the probable diagnosis of Down syndrome in their child, regardless of when the diagnosis occurs, should be provided with practical information that targets their specific needs (e.g., medical issues) and referrals for additional specialized care and medical services (Skotko, Capone, et al., 2009; Skotko, Kishnani, et al., 2009). Professionals should also assess the domains of parents' coping skills, satisfaction with life, and relationship functioning. Professionals should not assume the diagnosis will have a negative effect on parents; however, they should be sensitive and informed about how to assist parents who may be experiencing problems coping or adjusting. Navigating the plethora of information, which can be overwhelming to new parents, and identifying sources of support and encouragement is critical in adjusting to the news of their child's diagnosis and starting on a path for positive parent and child outcomes. Whether they receive the diagnosis prior to or after the birth of their child, parents need to be reassured that the intense range of emotions they feel is normal, but the new path they are on can have positive and rewarding outcomes, personally and in their marital and family relationships.

Key Messages From This Article

People with disabilities: Parents of people with disabilities have unique experiences and needs. We believe it is important to understand these unique experiences and needs as parents and as people.

Professionals: It is necessary to recognize that although parents may learn of their child's diagnosis at different points in time, prenatally or postnatally, they may experience similar levels of individual and relationship functioning.

Policymakers: Policy for parents of children with disabilities, regardless of the timing of the diagnosis, should provide support and promote their health and well-being.

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