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Family Sense-Making After a Down Syndrome Diagnosis

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Abstract

The script of parenting shifts when parents learn of their child's Down syndrome diagnosis. To build a theory of the diagnostic experience and early family sense-making process, we interviewed 33 parents and nine grandparents living in the United States who learned prenatally or neonatally of their child's diagnosis. The core category of *rescuing hope* for the future encompassed the social process of sense-making over time as parents managed their sorrow, shock, and grief and amassed meaningful messages that anchored them as they looked toward the future. Application of the theory to practice underscores the import of early professional support offered to parents at key points in the sense-making process: Early as they disclose the news of the diagnosis to family and friends, and later close friends and kin assimilate meaningful messages about what the diagnosis means as they recalibrate expectations for a hopeful future.

Keywords

Down syndrome diagnosis; doctor–patient communication; disability; family coping; qualitative; grounded theory; United States

Down syndrome is the most common diagnosis among genetically associated intellectual disabilities. The syndrome occurs in about one in 750 live births, with more than 200,000 people with Down syndrome estimated to live in the United States (Contestabile et al., 2010; de Graaf et al., 2017). A small region on the long arm of chromosome 21 is duplicated in this syndrome, with associated phenotypic features such as a characteristic facial appearance, short stature, hypotonia, and lifelong intellectual disability (Bull, 2011). Down syndrome co-occurs with other birth defects and medical problems, most commonly structural heart and digestive abnormalities and more rarely musculoskeletal, urinary, or

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Authors' Note

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respiratory anomalies (Bunt & Bunt, 2014; Stoll et al., 2015). In childhood, verbal skills, attention, and executive function are slower to develop and persist as deficits into adulthood (Grieco et al., 2015). Personality assets commonly associated with Down syndrome and supported by behavior research include a cheerful disposition, social nature, kindness, humor, and forgiveness (Grieco et al., 2015). These data tell us the “medical story” of Down syndrome, but offer little insight into the lived experience of how families come to understand the diagnosis and, ultimately, come to know their child with Down syndrome.

Qualitative and quantitative research results confirm that hearing the Down syndrome diagnosis is difficult for parents, whether the news is delivered prenatally or neonatally (Nelson Goff et al., 2013; Staats et al., 2015). Up to 72% of parents in the United States will opt to undergo noninvasive prenatal testing (Palomaki et al., 2013). Elective pregnancy terminations following a prenatal diagnosis of Down syndrome are estimated at 30% (de Graaf et al., 2015). Parents who terminate based on a prenatal Down syndrome diagnosis say it feels “right” to them, yet existentially burdensome with aspects of regret and grief (Lou et al., 2018). For parents who deliver a child with Down syndrome and affiliate with a Down syndrome organization, the vast majority express love for their son or daughter, pride in him or her, and a positive outlook on life (Skotko et al., 2011). Common to parents receiving the Down Syndrome diagnosis at any time is the process of sense-making about the diagnosis and, if they choose to continue the pregnancy, the integration of their child’s disability into family routines and family identity.

Background

Whether parents learn of the diagnosis prenatally or neonatally, emphasizing factual data from genetic testing overshadows the social dimension, specifically the parents’ desire to know what to expect if they raise a child with an intellectual disability. Past studies suggest that expectant parents imagine what their child with Down syndrome may be like over time, wonder whether they will face a life of suffering, and ask themselves whether their child’s life will have meaning (Skotko, 2005b; Van Riper & Choi, 2011). Parents also wonder about themselves. How will they face an unexpected experience of parenting a child who is different from typical children? Parenting a child with an intellectual disability, such as Down syndrome, poses a challenge to self-identity (Geuze & Goossensen, 2018; Lou et al., 2018; Whiting, 2013, 2014); How the parent embraces or merely adapts to such an identity depends, in part, on whether parents have access to cultural narratives and resources to inform their performance as a parent in ways that are socially understood and personally meaningful (Solomon, 2012; Van Riper, 2007b).

A useful approach to understanding family experiences following a Down syndrome diagnosis is to focus on the sense-making process. Weick (2001) asserted, “sense-making is a process of committed interpretation” (p. 11). The process is continual. Sense-making leads from a retrospective review of an experience to a review of alternative interpretations of the experience and then to choosing the meanings one assigns to the experience (Weick). It does not happen in a discreet moment. Sense-making is socially constructed through interaction with health care professionals, friends, and family members as parents question what to make of their situation and what to do next (Canary, 2008; Good, 1994). In the sense-making

process accompanying prenatal testing and fetal chromosomal abnormalities, parents consistently express a desire for “balanced information” and decision-making support, core tenets of genetic counseling practice (Skotko, Kishnani, et al., 2009; Van Riper & Choi, 2011; Weil, 2003). Even so, there is no professional or public consensus about what constitutes “balanced” information (Hippman et al., 2012). People with disabilities, advocates, and parents emphasize the helpfulness of understanding the day-to-day, experiential life of parents who choose to continue or terminate a pregnancy following a diagnosis of Down syndrome (Boardman, 2014).

Established guidelines for delivering a Down syndrome diagnosis were developed, in part, from parent and provider dissatisfaction with diagnostic conversations that were perceived as detached, haphazard, or negative (e.g., Skotko, 2005b; Skotko, Capone, et al., 2009; Skotko, Kishnani, et al., 2009). Yet how families hear the diagnosis (Morse, 2011) or engage in the sense-making process during and after the diagnosis remains on the list of what we need to know (Saul & Meredith, 2016). Qualitative research on early family sense-making after a neurodevelopmental disability diagnosis can complement survey-based research on diagnostic disclosure, parents’ satisfaction and resilience (Van Riper, 2007; Van Riper & Choi, 2011), and family members’ postdiagnosis roles and relationships over time (Korkow-Moradi et al., 2017; Yang et al., 2018). Describing the processual aspects of sense-making, families of children with Down syndrome may normalize phases of distress, satisfaction, and resilience in efforts to achieve “a renewed sense of hope” (Van Riper & Choi, 2011, p. 716).

The purpose of this grounded theory study was to develop a theory of family sense-making after a child’s Down syndrome diagnosis. The goal is to describe the sense-making process of parents and grandparents during the first 3 years, from the moment professionals disclose the diagnosis through the ensuing period of partnering with professionals, family members, and others to construct a future for their child and family. We focused on the early years of a child’s life because the initial adjustment to diagnosis is intense, emotional, and difficult for some parents. With changes in sociohistorical perceptions of disability and fetal testing practices (Skotko, 2005a), we aimed to capture current social conditions and medical practice.

Method

We used constructivist grounded theory (Charmaz, 2014) to describe processes of sense-making after the Down syndrome diagnosis of one’s child or grandchild. The methodology was well suited to our interests, given the philosophical tenets of symbolic interactionism and pragmatism central to understanding of what one does with a life event such as a child’s Down syndrome diagnosis in a particular historical time and circumstance (Glaser & Strauss, 1967; Heidegger, 1962).

Sample

After the University of Utah Institutional Review Board approved the study, the lead researcher used in-person purposive and snowball sampling to recruit participants at local events hosted for parents of children with Down syndrome and national advertisements hosted by private Facebook and other social media platforms specific to parents and

grandparents of children with Down syndrome. Every parent who participated voluntarily agreed to participate and signed the consent document approved by the Institutional Review Board. Because this was a study of the sense-making process situated in the contemporary genetic-information age, we purposefully recruited participants who had experienced the relatively recent diagnosis, birth, and early childhood (from 1 to 3 years old) of a child with Down syndrome. We sought a balance between those with prenatal and those with neonatal diagnostic news of Down syndrome. Allowing for at least 1-year postdelivery provided participants with the reflective time and social input essential to crystalize the process. Participants represented a range of experiences, including families of children with both minimal and extensive secondary diagnoses associated with Down syndrome and those with varying socioeconomic, ethnic, and religious backgrounds.

Thirty-three parents (21 mothers, 12 fathers) and nine grandparents (eight grandmothers, one grandfather) of children with Down syndrome took part in interviews. Learning of the Down syndrome diagnosis prenatally was slightly more common (17/33 parents and 6/9 grandparents) than learning of the diagnosis neonatally. The theoretical group interview included five parents (four mothers, one father) from the original parent sample. Participants were primarily White (85%), with a minority of Hispanic, Asian, and Native American participants. They were predominantly from the middle class and were well educated, with 87% of parents and grandparents reporting at least some college education. Analysis did not determine cultural differences in sense-making. All proper names were removed prior to analysis.

Data Collection

In-depth, unstructured interviews lasted from 1 to 1.5 hours and were audio recorded, professionally transcribed verbatim, verified, and anonymized using best practices for sensitive research (Clark et al., 2017). We offered local parents and grandparents who volunteered for the study the option of taking part in an in-person interview either individually or as a couple. Geographically distant participant interviews were conducted over Skype or the telephone. The initial interview question was, "Starting at the beginning, tell me about how you learned of your child's [or grandchild's] condition." We used probes to help participants continue their narration of the experience to the present time. New probes were added to interviews during simultaneous data collection and analysis, primarily to elicit detail about the properties and dimensions of the core categories and explanations about the sense-making process over time.

Data Analysis

Parent and grandparent data sets were analyzed separately using Dedoose Version 8.9.23 (SocioCultural Research Consultants, 2018), a web-based, qualitative-analysis software program. We used line-by-line coding to consider interview text. We also employed a process of constant comparison in analysis to consider how each interview differed from other interviews, how each code compared with other codes, and how text segments within codes cohered and varied. Abstracting from coded excerpts, we developed overarching categories and used axial coding to establish relationships between categories (Corbin & Strauss, 2015). During each phase of analysis, we referred back to coded interview text from

participants to ensure that meaning and comparability were preserved as we developed theoretical abstractions of the data. We present here the overarching, process-oriented account of parental sense-making.

We maintained rigor throughout analysis in several ways. First, each research team member recorded analytic memos during the coding and analysis process. We also recorded personal reflexive memos. The principal investigator directed team discussions to enrich, synthesize, and extend the memos during team-based analysis sessions (Rettke et al., 2018). Second, rigor in analysis was aided by a supplemental analytic strategy. For the diagnosis (professional–parent) and disclosure (parent–others) processes, we conducted a matrix analysis (Averill, 2002; Miles et al., 2014). Matrices organized data about who offered diagnostic information to the parent(s), to whom the parents disclosed the diagnosis, in what timeframe, and the medium of disclosure. Third, after analysis was complete, we tested the explanatory power of the emergent grounded theory using data from first-person parent and grandparent narratives, blogs, and memoirs. As a form of theoretical sampling, the addition of secondary data enriched our abductive analysis of contrasting case pairs: mothers and fathers, parents and grandparents, and those who experienced prenatal or neonatal diagnosis (Conlon et al., 2020). We used focused coding on the secondary sample of extant parent narratives to assess how well the grounded theory fit the new data and how well the new data fit the theory. Constant comparison of the data to the theory allowed us to test the robustness of the emergent grounded theory with an expanded data set, as recommended by grounded theorists (Corbin, 2009; Corbin & Strauss, 2015). Fourth, we finalized and verified our analysis by hosting a theoretical group interview (Morse, 2007) with parents purposefully selected from parent-interview participants. We chose parents for the theoretical group interview who offered a variety of perspectives and information-rich accounts (Patton, 2002). The purpose of the theoretical group interview was to share the emerging model with those who had lived the experience and ensure saturation of core categories and the overall grounded theory process. We chose parents who had both easier and more difficult experiences; we also included both mothers and fathers. The theoretical group interview verified saturation, concluding data analysis.

Results

As participants narrated their experiences of family sense-making, they started with early stages in the process: the riving moment of *hearing the diagnosis*, followed by the immediate search for information to offset and positively reframe the news. Managing their own and others' reactions to the diagnosis followed. Before they had made sense of it themselves, parents felt compelled to disclose the diagnosis, first to their own parents, then to others in the family, and finally to friends. The core category of *rescuing hope* for the future encompassed the social process of sense-making over time as parents learned to answer questions about what this diagnosis meant for their child and family. We describe the properties of rescuing hope: telescoping into the future, recalibrating expectations, integrating meaningful and memorable messages, and owning identities. Finally, we discuss grandparents' contribution to rescuing hope through family sense-making as *treading lightly*. A representation of the process is provided in Figure 1.

Feeling Torn Apart by the Diagnosis

Prenatally, parents learned of their child's diagnosis from an obstetrician, nurse, or ultrasound technician. Those who learned prenatally were pleased they had time to prepare by looking up resources and letting others know about their expected baby. "We did a Facebook countdown and slowly revealed it," said one mother. They wanted people to see the baby's birth as a new adventure and shared the news before his arrival. Those who heard after the child was born were informed of the diagnosis by a pediatrician, nurse, or genetic counselor. They were glad because it "would have ruined that 9 months," causing unnecessary worry, and led them to be "stressed out in my pregnancy. And that isn't good."

Both the parents who learned of the diagnosis prenatally and those who heard postnatally recounted the diagnostic event with visceral vividness. The news was "tearing me apart," they said, and so difficult to hear that they plunged into a state of shock and emotional suffering. Some parents hoped the clinical diagnosis was untrue and that definitive tests would negate the diagnosis: "I was just looking for something to make me feel better. I almost wanted them to tell me, 'Your child doesn't have Down syndrome and you're fine. Everything is going to be fine. He's perfectly fine'." Feeling guilty for wishing the diagnosis to be false compounded the grief. Those who heard prenatally described similar feelings of shock and grief, followed by a gradual uptake of the news. One mother stayed in bed for a week, another had "crying breakdowns" periodically for a month. Those who received a neonatal diagnosis faced a compressed timeline to make sense of the situation. As one mother said of the pressure to assimilate the news quickly,

We took some pictures in the delivery room, and then they took her, and he [the baby's father] followed her to the newborn nursery, and I was all alone. Just me and the nurse. And I was thinking, "I haven't even had time to talk to my husband about this. What does this mean for us?"

Another mother said of her early reaction to the neonatal diagnosis: "Part of me felt bad that I felt that way [grief-stricken]. This isn't the end of the world, you just had your baby. And you're supposed to enjoy her. But you don't." The guilt parents felt at their own disappointment and sadness added to their distress.

The diagnosis was most often presented to both parents simultaneously, although a subset of parents reported hearing of the diagnosis alone and then facing the daunting responsibility of disclosing the diagnosis to the other parent. Mothers who heard the diagnosis alone reported hearing the news casually or surreptitiously from an ultrasound technician or from an obstetrician at a routine visit. Fathers who heard the diagnosis alone were in the newborn nursery. One mother described bringing her three children to the ultrasound appointment, with pink and blue balloons so they could have a family gender-reveal party together. As the technician found concerning markers, the children left the room and the mother received the Down syndrome diagnosis alone. Overcome with emotions, the mother called her husband to share the news, then told her children the party was postponed. The parents delayed talking with their children until they could all be together that evening.

A father reported how the pediatrician told him the diagnosis in the nursery while the child's mother was still in the delivery room. He said, "You know, we've gone through everything

and we've looked at the markers and stuff, and we think that your son has Down syndrome." The pediatrician then added, "You know, everything's going to be okay." The father said, "She was sweet, but it was just kind of uncomfortable. I just said, 'I need to go and see my wife. I need to tell her'." The pediatrician said, "No," and recommended "that I didn't tell her for at least two or three days, while she was on medicine and stuff." Unwilling to delay, the father walked to her hospital room. "She looked at me and knew there was something [wrong], and we both started crying, and we talked about it." The burden of knowing shouldered by the parent who learned first was surpassed only by the challenge of telling the other parent. A mother recounted,

[My husband] told me [that telling me the diagnosis] was one of the hardest things he's ever had to do. And we have a cool picture of us holding our son in the delivery room as soon as they sewed me up. You can see the joy and excitement in my eyes because I have no idea that he has Down syndrome. And my husband's eyes are just red. I thought he was crying because he was so happy. He was crying because he was terrified about how he was going to tell his wife our son has Down syndrome.

Professionals who delivered diagnostic news to only one parent were uniformly criticized. Even when parents were together at the time, nearly every diagnostic information exchange met with some level of parental critique. "She was grim," said a parent. "She was serious, no emotion at all," said another. "No 'Congratulations, you're in for a whole new experience with a kid who will change your life' or anything like that. Just, 'Your child has Down syndrome'."

A mother and father who took part in a dyadic interview shared a positive prenatal diagnostic experience. The physician telephoned the parents at home with a conclusive genetic confirmation of Down syndrome. In that same telephone call, the physician also said their child was a boy. "I liked her," said the father. His wife said, "She arranged another meeting for us to come in." In the interim, they talked to each other and cried. Every parent in our study cried after hearing their child had Down syndrome, and they described their emotions vividly. "I was listening but I couldn't hear, I couldn't comprehend," explained one mother. I was "shocked" said another; "It was scary," said others. "I was ignorant, that's why I cried," said still another parent. Parents agreed it "takes you a little while to gather your thoughts and figure out what you feel like, how you want to carry on, what you want to do."

Curating Balanced Information

For parents who received a clinical diagnosis, a tense period of waiting for conclusive genetic confirmation lasted several days, and parents vacillated between the shock and despair they felt when they heard the diagnosis and a growing sense of positive possibility. In these early days, parents spent hours seeking and integrating what they considered balanced information. They questioned negatively framed information and considered positive, imagined futures compatible with the diagnosis. For parents who received a neonatal diagnosis, many searched the internet for images of babies with Down syndrome so they could see whether their baby looked like other babies. Sometimes the physician or social worker also offered sequential information and support, scaffolding with parents a

new understanding of the diagnosis in a broader perspective. Although information seeking began immediately following diagnosis, seeking continued over time. The kinds of information sought changed in emphasis throughout parents' and grandparents' sense-making process.

Most parents and grandparents realized they did not have deep, personal knowledge about the experience of people with disabilities. So, they started their information seeking on the internet, using Google or other search engines to find pictures, stories from families of children with Down syndrome, and medical facts. Others purposefully avoided the internet and instead sought expert advice through books, conversations with clinicians, and other sources they emphasized were "credible." Parents were hungry for information that would help them make sense of what to expect for their child and their family. As they encountered more information, they described feeling overwhelmed by the volume of new information that surfaced, some of it unwanted or ill-timed. One mother explained,

We didn't have a firm diagnosis yet. And after my husband left for the day, a social worker came in and said, "I hear your child has Down syndrome; here's all the resources." And as soon as he left I started crying hysterically. No one told us it was a for-sure diagnosis. I thought it was just a possibility. We probably needed those resources, but I wasn't ready to deal with it. I threw it all away. It was too soon, I needed a chance to come to terms, and the hospital didn't feel like the place to get that information.

Participants noted that they did not appreciate information that they interpreted as flatly negative. It was not helpful to them because their central challenge was constructing a positive mindset to live with their new reality. One mother recounted, "I felt like I needed happy stuff. I didn't want to read through other people being sad about this happening to them, too." Some professionals were helpful in this regard, as one mother noted:

And it was that [doctor] who set me up for success because otherwise I would have no idea. And I sure wasn't going to Google it, I didn't need that. He was like, "Here's your goal. Your goal is to maximize her potential just like any child."

In this case, curating information meant that the parent avoided the all-inclusive and unweighted information dump provided by an internet search. Relying instead on her doctor's reminder about core parental responsibilities, she was able to release diagnostic details and focus on the central parental task: raising a child. In contrast to the "happy stuff" she believed she needed or the "setup for success" information parents said they craved, parents were alarmed by professional recitations of co-occurring medical problems and a futuristic timeline marked by peril. Participants found information of that variety overwhelming rather than useful, as one mother summarized: "I think the medical profession should be more compassionate about it, and not be so negative, fact-oriented."

As they gathered information, parents held fast to meaningful, memorable messages about having a child with Down syndrome. One mother recounted in her blog that the neonatologist "threw [the diagnosis] out there between his blood sugar and his blood pressure," shrinking the significance of the diagnosis so she could see Down syndrome as just one more descriptor of her baby. One mother who wrote her account of the phase of

curating information recalled how the pediatrician connected the diagnostic news to sense-making in a way that was straightforward and practical:

She did not follow up with an apology or pity. When she saw the quiet tears streaming down my face she paused and asked what was wrong. I wanted to tell her how she shifted my world. I said to myself, as much as to her, “Now what?” She looked at me as if she was having a hard time understanding my concern and said, “We treat him just like any other baby.” (Dickinson, 2016)

“This is how we make sense of it,” the pediatrician was saying: “We treat him just like any other baby.” Balanced information was more than a golden mean between positively and negatively framed facts, but a balance between the *what* of Down syndrome—facts, risks, comorbidities—and the *how* of parenting that child. In curating balanced information, parents circumscribed the definitive facts about a child’s diagnosis to also allow for a hopeful future and the possibility of an ordinary life, as they would have with “any other baby.” To imagine a hopeful future, parents held a heightened regard for compassionate, personal accounts to wrap around the facts. The early conversations between parents and providers near the time of diagnosis extended to other family members as parents—ready or not—believed it was their responsibility to disclose the diagnosis to family and friends.

Managing Emotions When Disclosing to Others

Once the diagnosis was confirmed, parents began planning how to tell others. Their own shock and dismay still fresh, they felt compelled to share the news with others. Braced for others’ emotional reactions that mirrored their own, they braced for clumsy or ignorant responses. Parents told their own parents right away, typically on the very day they learned of the diagnosis. Disclosure to their siblings, other children (if any), and finally, friends, occurred next. Approximately 20% of parents used social media to disclose widely, often with pictures of the baby and family (see Figure 2). Parents who chose social media said the time they spent writing a careful explanation helped them convey through their own story and picture a hopeful future they aspired to, but had not yet fully mastered.

Disclosure was an early component of sense-making, as explaining the diagnosis invited a dialogue. Together, parents and their close friends and kin began to consider what the diagnosis meant in light of the past, present, and future. When telling friends the news of her son’s diagnosis, one mother said, “You catch them off guard. They don’t know what to say. ‘Do I say congratulations?’ ‘Do I say I’m sorry?’” Mirroring her own reaction to the diagnosis, this mother reported that her “family started crying” when she told them. She knew what they were feeling, and their feelings reflected her own. This pregnancy had been long awaited, and “they had ideas of a baby in mind, and after all the time and effort we put into getting pregnant, a kiddo with Down syndrome is not what people typically want.” Whereas dwelling with the diagnosis and feeling torn apart were intensely personal and even isolating, disclosing took that news to an interpersonal venue where reactions mimicked and amplified their distress. Seeing and feeling the emotionality of her family galvanized one mother, who realized that she had accepted the diagnosis and needed her family to know it was time to “move on.” She said, “If I had a choice, both for him and us, I would prefer that he didn’t have Down syndrome. But he does. So we move on.” The discussion that followed

the disclosure of the Down syndrome diagnosis helped families make sense of their unexpected situation. By rehearsing for the first time a way of talking about Down syndrome and their newborn, they practiced sharing both *what* Down syndrome facts were and *how* they imbued those facts a valence of import and affect.

Rescuing Hope

Rescuing hope—was the core category or main theme encompassing the sense-making process. Rescuing hope followed hearing the diagnosis and disclosing, and described the work of situating meaning about the Down syndrome diagnosis in the present as well as the future. Hope was a key to sense-making, as families managed their sorrow, shock, and grief and amassed meaningful messages that anchored them as they looked toward the future. They envisioned a future they described as “more alike than different” in comparison with their expectations of family life with a child without Down syndrome. The dimensions of rescuing hope included telescoping into the future, recalibrating expectations, integrating meaningful and memorable messages, and owning identities.

Telescoping into the future.—A stoic new father explained how the diagnosis propelled him to think ahead, imagining the entirety of his child’s life. It was not particularly hopeful and featured disappointment: “At some point you’re thinking when he’s turned eighteen, our kid would be gone and stuff, but that might not be the case, so . . .” His wife tagged on, reframing to craft a more positive vision, “I mean, there’s still a possibility of driving or going to college. It would be probably different. And maybe not.” We called this process *telescoping into the future* to describe how parents looked at the horizon and imagined the events and milestones in their cultural script for their child. Zooming out, they could see a lineup of expected markers through childhood and adolescence, indicators of a child’s life well lived. Driving, dating, going to prom, attending college, getting a job, and living independently were milestones often mentioned. Parents grappled with the potential loss of those moments and events, as well as alternative means of achieving them. One mother said,

I was sad for the life we had planned for her. I was just sad for her. A wedding, boyfriends, prom, things that she might not do now (which she might), but like my mom said, it was a loss of a life that I had planned for nine months.

Parents who were telescoping into the future *recalibrated expectations* with the information they gathered about Down syndrome:

We Googled. I wanted [the Internet] to tell me the future, and of course it’s not going to do that, but I think a lot of parents want that. How is she going to act when she’s two? How is she going to act when she’s five? What can we expect? You’ll never know, but you’ll never stop looking, either.

Recalibrating expectations.—As parents telescoped into the future, they looked for older children with Down syndrome and their families and followed them personally or on social media. They observed recalibrations, or ways families experienced developmental milestones like team sports, prom, or college, adapted to their child’s assets and interests. Grandparents, too, recalibrated: “I think it kind of grinds you down to the point that you really do understand that every child is an individual.” No child progresses from milestone

to milestone in a predictable rhythm. Their own grandchild, they reasoned, would have her own rate of growth, too. Reflecting on the past year, one grandmother said, “I think you are always looking for two things, looking for the next steps, what you can expect, but you also want to see what’s possible.” The news of Down syndrome required a double re-consideration. First, the diagnosis changed the idealized steps to adulthood that they had in mind for the child. Second, they reflected on a new kind of caregiving future for themselves, perhaps a caregiving future without a terminal endpoint.

Integrating meaningful and memorable messages.—Recalling her hospital stay, a mother spoke of the transition from feelings of a lost future to a more hopeful state by *integrating meaningful, memorable messages* of positive potential in the future. Unable to sleep, and overcome by anxiety and grief, she met with the social worker early in the morning. The nurses suggested that she visit with him:

[My husband and I] told [the social worker] that they thought she had Down syndrome. And he got the biggest smile on his face. He just said, “I just think that’s great.” I was just like, huh? Because at this point, I’m reading about all these horrible things. He said, “They’re wonderful people and they make such contributions to the community. She’ll make you a better person and your husband a better person and your entire family better people. So, it’s just going to be wonderful.” It was awesome. It was exactly what we needed to hear; some reassurance that regardless of what ended up happening, it was going to be okay.

Providers throughout the health care system were the primary sources of hopeful and memorable messages, but not exclusively. Some messages came from strangers, friends, or family members.

Some parents explained that anger and disappointment continued, incompletely resolved. This was particularly true of parents who received normal prenatal screening results and then a neonatal Down syndrome diagnosis, and for parents of children with significant medical challenges. One parent reflected on the past 3 years with her daughter, and mused that perhaps they could have chosen termination if the prenatal test results had been clearer. When people told her how “marvelous it is to have a child like that,” she rejected the sentiment completely. “We felt we had no choice,” she explained, “We were stuck with this baby.” Her major concern for months after the birth was “How do you deal with that?” She described attending conferences and parent groups looking for solace, when she had a fortuitous encounter with well-known parent advocate. “She told me, ‘in the end, this is just a baby that needs her parents’. And that’s the thing that helped me go through this whole thing,” she concluded. After repeating this thought about her baby’s need, she was able to “get through” months of serious medical problems and difficulty connecting with her baby. Like other parents, she was looking for hope and found it in a memorable message so mind-sticking that she could quote it word for word in an interview years later.

In addition to interview data, first-person narratives in the secondary sample supported memorable messages as the hallmark of rescuing hope. To loosen the grip of grief, shock, and the tearing apart sensation that followed the diagnostic news, parents were receptive to alternate ways of viewing their situation. A mother wrote, “our grief wastes us. We have

such anger but won't admit to it." The feeling of being torn apart did not abate for weeks: "I rage. I don't want more boulders to climb over. I don't want more grief to cope with. I don't want a child who will look different. I cry and cry until I am empty" (Van Tighem, 2000, pp. 179–180). The memorable message in this case unfolded without words. As they visited the pediatrician he unwrapped their baby with infinite gentleness. "He smiles down at her, speaking softly and crooning, looking deep into her fascinated eyes. He handles her as though she were precious and wonderous. We watch. We soak it up. We are given a lesson in valuing her" (p. 180). Borne of suffering, parental readiness to reframe the situation and imagine a new and hopeful way forward come in many forms.

Like the parents who saw someone valuing their baby, others, too, replaced negativity with positive, inspirational ways of viewing their life with a child with Down syndrome. One mother explained their motivation to locate meaningful messages: "We just wanted to be happy." Another woman said her husband embraced a message in song: "My husband took on Bob Marley's song, 'Everything's Gonna Be Alright'. He played that on repeat. That kind of became our little mantra: It's gonna be okay." Memorable, positive messages gave parents a touchstone as they worked to rewrite hopeful expectations for the future. Some messages distilled into a single line: "She is just like everyone else in some really important ways: She's here to learn and to grow"; "Never expect less." Living in the moment was a powerful message. Parents shared different versions of how to do that. One said, "Take a deep breath and hold him." A message emphasizing parents' responsibilities and a child's potential was, "Do everything you can to help him fly." One family of a child with Down syndrome known to participants in this study took the idea of flying literally, and the father created a photographic calendar featuring his child "flying" (Durando & Bowerman, 2015).

Owning identities.—One mother explained how she arrived at a new, hopeful narrative for the future as she contemplated her 3-month-old daughter:

I talked to a lady, and she said, "It's funny how we do that. We're thinking about prom, and all we need to worry about is taking care of this little baby." And after the fact, you realize that made no sense whatsoever. I was worried about her getting her first job, and graduating from high school, and being able to live on her own, and making friends. And here, I had a baby; I just needed to worry about a baby. But that's where I was at that moment. It's just going through her entire life and wondering what her entire life would end up being.

By telescoping ahead to prom, she named and then recalibrated her expectations. Her breakthrough was that her baby was "just a baby," and her job was to take care of a baby, not to dramatize an unknown future and preemptively grieve its loss. We called this part of the sense-making process *owning identities*, because participants conveyed that they started owning their own identity as the parent of a child with Down syndrome. Owning this parental identity meant accepting their child, recognizing similarities and differences as part of both their child's identity and their own.

Anchoring parenthood in the here-and-now by reminding themselves their baby was "just a baby," parents resisted the exceptionalism of a disability identity and recast their expectations as those of any parent. Guided by their child's individuality, they found

common ground with the cultural expectation that parents help their unique child to thrive. A mother gratefully recalled how her pediatrician helped her recreate her story as the story of any parent:

I don't know why this sticks in my mind. But he said, "I'm going to give you guys one piece of advice." He said, "It's the same advice I give every parent regardless of what kind of child they have: Don't compare her to anybody else. She's her own person. She'll do things at her own pace. She might not ride a bike at five. But she's probably going to ride it at eight or ten or eleven, but she will ride a bike. Don't compare her to everybody else, and just let her develop and move at her own pace. And she'll get there. She'll do it."

The positivity parents craved within the normalcy of the parenting experience was recrafted to emphasize "it's just a baby," or "she's on her own timeline, she'll get there eventually." This positive, "normalcy" narrative was amplified further by parents who noted a super-normal discourse common in Down Syndrome Foundation products. Down syndrome was a "gift" according to some mothers, and it was not hard to find denim overalls that said Down syndrome is "extra special" or "Up with Down syndrome":

Finding and "holding hope was the thing," said one mother.

A big thing, you know? And you feel completely overwhelmed, and probably sad. And that's okay. You can feel sad, just try not to let it last forever. Because we've all felt that sinking feeling because your life is not what you thought it would be. Your baby's life is not what you thought it was going to be. But that's okay. It'll be different, and it'll be harder. But it's okay, because it's fantastic.

Another mother made similar comments: "It sucks. But I'm going to love this baby. I'm going to tackle it [the experience of parenting a child with Down syndrome]." They stated that the differences "become your new normal, no matter what, and you just go with it." These parents crafted their own memorable and hopeful messages that integrated both their disappointment and their love and optimism. Those messages resonated with parents and grandparents by affirming core values about families, namely a belief in their child's potential, their job of loving and caring for their child, and a hopeful and positive future as a family.

Treading Lightly

Like parents, grandparents experienced shock and sadness, then began information seeking soon after their adult children shared the diagnosis. Treading lightly explains how grandparents walked with parents in the family journey of sense-making, aware of the centrality of parenthood and the vital contribution of extended family in support of parents and grandchildren. Grandparents wished to be close and supportive, yet tread lightly enough to avoid intruding. By updating their knowledge of Down syndrome, some reflected on how much society has changed since Rosemary Kennedy's lobotomy (Larson, 2015). Back then, "we used to call them Mongoloid children, now it's kids with Down syndrome, not Down-syndrome kids." They guarded against interfering in their adult children's family life: "Our kids are the parents, so you're definitely in a support role" as a grandparent. They also restrained themselves from inserting a focus on their own sadness or adjustment process.

“Cut your own drama,” said one grandmother. “It’s not about you. Do whatever you can to make it an easier experience [for them].” Another grandparent advised, “Learn what you can and share it at the appropriate time. Your kids don’t want to hear it all at once.” To avoid overstepping, “tread softly,” admonished a grandmother, “and just do what you can behind the scenes.” The complement to rescuing hope for parents was the parallel grandparent contribution of supporting parents’ sense-making from an engaged but more peripheral position. Overall, the process of family sense-making included grandparents’ unique supportive contribution. Maintaining an awareness of parents’ needs, grandparents offered emotional and informational support while treading carefully to avoid overshadowing parents’ needs.

In summary, grandparents accompanied parents in a family sense-making process. The time of diagnosis was wrenching for parents. Grandparents were among the first people to whom parents disclosed the diagnosis and were background supporters of the parents. Grandparents viewed their contribution to the process of family adjustment as treading lightly to support the family as they refashioned their expectations for the future. Curating balanced information helped parents manage their disclosure message to others and opened dialogues that were sometimes painful and often comforting. Professionals were present at key moments in the process of sense-making, from diagnosis through medical management. Parents described how professionals either capitalized on or missed opportunities to help families craft meaningful and memorable messages that could anchor them through the process of rescuing hope for a positive future. Using both their personal resources and professional input, parents sought information and resources to aid them through the sense-making process after a Down syndrome diagnosis. They rescued hope by creating a positive narrative of parenting and potential.

Discussion

The grounded theory of rescuing hope is a theory of family sense-making in the context of having a child with Down syndrome. Rescuing hope is an ongoing social–psychological interpretation of parenting, relating to others, and enacting a cultural script of family while raising a child with Down syndrome. Parents’ emotions at diagnosis were similar between those who learned of the diagnosis prenatally and those who learned neonatally, a finding also noted in a large mixed-method survey (Nelson Goff et al., 2013). Parents recalled the diagnostic interaction vividly, a finding referred to by Skotko (2005a) as a “flashbulb memory” because of its indelible quality. Most often, parents in this study and others reported professionals as being cold, pessimistic, and unsupportive at the time of diagnosis (Staats et al., 2015) and their own initial reactions as grief-stricken and overwhelmed (Pillay et al., 2012). Perhaps because of updated, evidence-based guidance about how to deliver a Down syndrome diagnosis (Skotko, Capone, et al., 2009; Skotko, Kishnani, et al., 2009), some parents in this study reported professional compassion, positivity, and messages about a meaningful life ahead. Parents savored those interactions, whether they heard those messages at the time of diagnosis or thereafter. Findings from the current study contribute nuanced understandings to previous investigations of parents’ experiences with diagnosis and parenting of a child with Down syndrome. We add to the accumulating evidence that parents reject a hegemonic, medicalized discourse of chronic sorrow, suffering, or tragedy at

the birth of a child with Down syndrome (Lalvani, 2011) and construct instead a narrative of parenting that is “more alike than different.” Family members in this study, like participants in similar studies, “did not seem to view their lives as very different from the lives of parents raising children without disabilities” (Lassetter et al., 2007, p. 464). Our grounded theory of rescuing hope through ongoing sense-making holds implications for theory, research, and practice.

Theoretical Implications

Beginning with the unexpected diagnosis, parents ask themselves what this means for them (cf. Skotko, 2005a). They describe making immediate medical decisions, searching for and receiving information, and disclosing the diagnosis to close family members. Professional support of parents’ adjustment during the first year postdiagnosis offers parents the opportunity to share their sense-making process. Professional support during this period is something parents would welcome, although some participants in this study echoed findings in previous studies by describing delivery of their child’s developmental disability diagnosis as blunt and insensitive (Elwy et al., 2007; Skotko, 2005a). As a social, interactive process, sense-making only begins at diagnosis. According to participants in this study and in prior studies, interactional features of the disclosure by professionals influence their sense-making process. Although *feeling torn apart* was common, that experience was either softened or exacerbated depending on who, how, and when the diagnosis was delivered to parents.

Synthesizing diagnostic news and accepting it takes time (Canary, 2008; Morse, 2011). Our grounded theory of rescuing hope through sense-making builds on a resilience model of family adaptation (Van Riper, 2007) by identifying specific features of the sense-making process that lead to the family resource of rescuing hope. Rescuing hope does not deny the paradox of disability, that one’s child and one’s family life will be both joyful and tearful, uplifting and challenging. Rather, sense-making to rescue hope encompasses the lived experiences that take time to process, interpret, and constitute as family resources for adaptive functioning. Participants *curated balanced information* and *managed emotions* as they worked together and with others to attend to positive experiences and their child’s abilities as they rescue hope, as detailed in other studies across a larger age range of children (Farkas et al., 2019). Findings across studies suggest that parents apply sense-making resources from their spiritual and religious backgrounds to their daily life, including a sense of their purpose as parents and life as a journey of growth (Marshall et al., 2003; Pillay et al., 2012). Focusing on family sense-making to rescue hope provides texture to previous study findings of parent experiences, with participants recounting with vivid clarity their interactions, actions, and turning points that establish a positive assessment of a successful future.

In delineating the concept of hope, (Morse & Doberneck, 1995) defined hope commensurate with the findings of this study. Hope is “a response to a threat that results in the setting of a desired goal” and “use of all internal and external resources and support that will assist in achieving the goal” (or, we might add, their expectation for the future). In doing so, parents “revision the plan [of parenthood] while enduring, working, and striving to reach the desired goal” or expectation (p. 284). As families press against despair to reformulate “hope

pathways,” as Morse & Doberneck (p. 284) aptly named the revisioning process, they actively revised their goals and expectations for the future. The concept applies in this situation, and the pattern or typology of rescuing hope adds to the conceptual elaboration by extending hope from a personal to a family experience. Four patterns of hope, developed from experiences of individuals on their own behalf, applies in new ways to a typology of hope for one’s child and family (Morse & Doberneck, 1995).

The grounded theory of rescuing hope is inclusive of disparate family experiences. There is no linear progression, but rather an iterative interpretation that involves both looking forward (i.e., telescoping into the future; recalibrating expectations) and staying in the moment (i.e., integrating meaningful and memorable messages; owning identities). Rescuing hope is a family experience, with grandparents noting that their way of facilitating sense-making and rescued hope is to tread lightly as a resource to their children and grandchildren. As such, rescuing hope is a family resource that represents an asset approach to the experience of having a child with Down syndrome. Such an asset approach also provides practical implications for guiding parents in building and leveraging their resources for the benefit of their families.

Practical Implications

Parents declaratively stated the need for meaningful messages and materials from clinicians to aid them in sense-making as they construct a revised narrative of family. An actionable intervention, suggested by parents in the theoretical discussion group, was to create videos about real families with a child with Down syndrome, including the positive experiences and daily challenges they face.

Anticipating their concerns and guiding them in disclosure—exploring what to say and how to share it with closest kin, extended family, and others—can minimize distress and maximize integration of the experience into family identity and life plans. The family experiential process continues after disclosure, as well. Families synthesize new identities that integrate positive expectations for themselves, their child, and the family into the future. Some resilient parents arrived at expectations for the future that sounded like any parent’s expectations: Their child is “just a baby,” with needs for safety, security, and growth like other babies (Korkow-Moradi et al., 2017). Meaning can be explored and constructed throughout the sense-making process as professionals validate parents’ acknowledged losses. Professionals can also assist parents to connect with others and settle into their new identity (Bentley et al., 2015; H. A. Douglas, 2014; T. Douglas et al., 2016; Neimeyer et al., 2010).

The shock of the unexpected diagnosis receded as parents reconnected to cultural scripts about taking care of a baby on a day-to-day basis and helping their child achieve their potential. Fostering parental resilience using theory-based models (Van Riper, 2007) and curated information (T. Douglas et al., 2016) meets their need for sense-making resources. As in earlier studies, participants in the current study strongly endorsed being informed by a team of knowledgeable professionals in a timely and supportive manner. The moment of disclosure is an indelible moment. It can either catalyze sense-making or create unnecessary hurdles to begin the process. Conversation analysis between experienced medical and

education professionals in London and parents receiving a developmental disability diagnosis for the first time also concluded that hopefulness and purposeful discussion of the child's potential in the future was aligned with greater parent and professional satisfaction than diagnosis framed in more fact-oriented ways and limitations-based ways (Bartolo, 2002). Such discussions need not deny the conflicting emotions parents will feel or the paradox of parenting. Indeed, facilitating sense-making allows parents to embrace the paradox of parenting any child, and especially children with Down syndrome.

Future Directions

Rescuing hope likely applies to family sense-making in other disability and chronic-health-challenge contexts as well. Families have a variety of interpretations to choose from as they make sense of disability, ability, potential, limitations, expectations, and relationships. The results of this study add unique insight to the extensive literature on families of children with Down syndrome by focusing on the processual experience. The grounded theory identifies stages and phases of family adjustment to arrive at a hopeful and meaningful future, with points of intervention aligned with the process of sense-making. By focusing on the dynamic of family sense-making after a Down syndrome diagnosis, this study complements more static, categorical research on family responses to the diagnosis of a child with Down syndrome (Hastings, 2016). Parents in this study reported that too often, clinicians, other parents, and society at large view their experience as pitiable. Research on families with a child with an intellectual disability does, indeed, arise from implicit assumptions about caregiving burdens, parents' mental-health challenges, and marital stress, missing the balance of resilience and positive parenting experiences (Cless et al., 2018; Hastings, 2016; Jess et al., 2017). Researchers and clinicians can more confidently consider sense-making resources aligned with families' processual experience, drawing on newer scholarship about positive, hopeful futures and the processual, family-sense-making journey.

Conclusion

Health care personnel strive to deliver unbiased, factual, scientific information. Studies on delivering so-called bad news describe ways clinicians can successfully transmit neutral factual information with empathy. After receiving a Down syndrome diagnosis, parents find hope by reconfiguring the cultural values of individuality and developmental achievement. They accommodate and repurpose those values to include raising a child who is different but still a child. They can recast the cultural script of parenting, retaining purpose: Their child needs parents who can help him or her achieve his or her potential. The time has arrived to update the clinical narrative to offer hope-affirming messages to parents more deliberately and at earlier points in their sense-making process.

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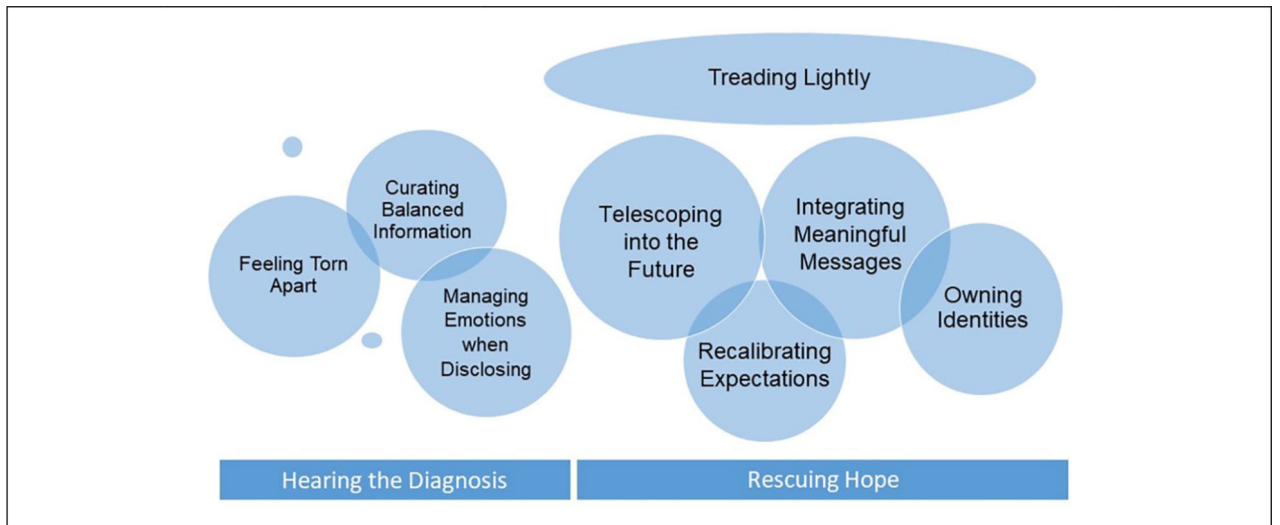


Figure 1. Rescuing hope: a grounded theory of family sense-making after a child's Down syndrome diagnosis.

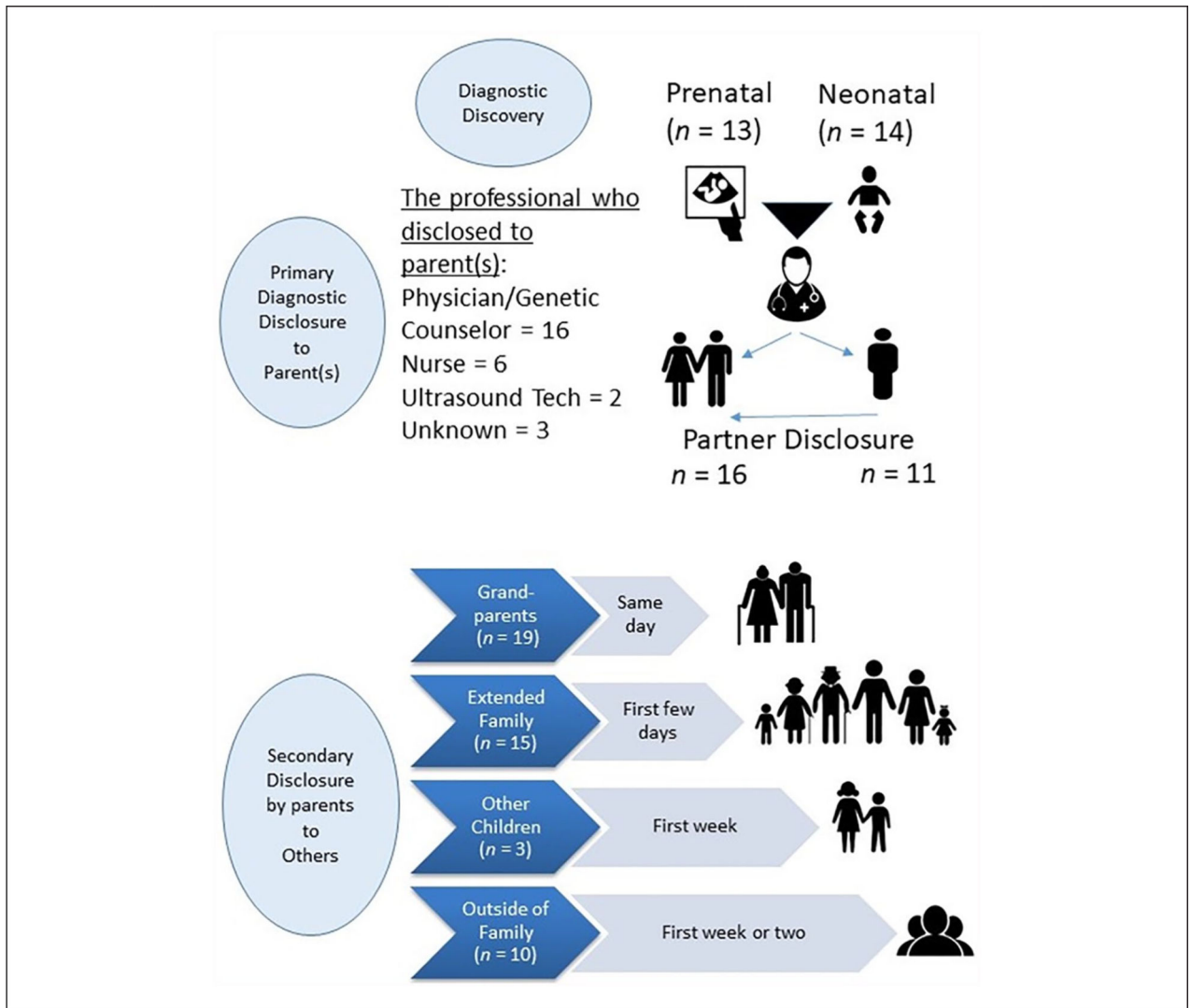


Figure 2. A conceptual representation of the primary diagnostic disclosure to parents of their child’s Down syndrome diagnosis and the ensuing sequence of secondary disclosures by parents to others.

Note. The 33 parents who took part in 21 interviews disclosed to multiple others.