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The Transformation Process of Fathers of Children with Disabilities: An Exploratory Case Study

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Introduction

A growing body of literature from the past decade recorded a shift in American families from the traditional role of fathers as breadwinners, to fathers taking on a more active role in parenting and caregiving (Lamb, 2000; MacDonald & Almeida, 2004; Bosoni, 2014). In general, this has been viewed as a positive shift, acknowledging fathers' contributions to child development and family well-being (Solomon, 2014). Daly and Palkovitz (2004) suggested that while equally important, fathers' contributions to the family, and therefore, their support needs, were different than mothers'. However, the majority of research in child development is geared to mothers as primary caregivers. This gap in the literature is more acute relative to fathers of children who have disabilities.

There was ample evidence that parent involvement was key for successful outcomes for children with disabilities (Gallagher, Rhodes, & Darling, 2004; Mahoney & Wiggers, 2007; Sawyer, 2015). The majority of research examining how to facilitate parent involvement when children have disabilities involves mothers; however, several studies have found complementary, yet distinctly different, experiences between mothers and fathers (Pelchat, Lefebvre, & Perreault, 2003; Hastings, Beck, & Hill, 2005; Pelchat, Levert, & Bourgeois-Guerin, 2009). Studies related to parenting by fathers of children with disabilities was sparse.

Family systems theory (Bowen, 1966) points out that family members are inter-related; the experiences and perceptions of one member affect all members of the family. Examining the experiences of fathers of children with disabilities can lead to improved understanding of the family as a whole, assisting human service providers in appropriately offering support (Appelbaum & Smolowitz, 2012). Ly and Goldberg (2014) suggested that because disability fields are often female dominated; there may be a father specific barrier in accessing support services. Carpenter and Towers (2008) found that two factors either facilitated or hindered involvement of fathers of children with disabilities: 1) time to engage and 2) how professionals responded to fathers when they were present. Scarce literature is available to guide professionals on how to appropriately support fathers in positive parenting with their children who have disabilities. To address this gap in knowledge, the current study seeks to understand the transformation process of two involved fathers through a case study approach in an attempt to assist professionals in appropriately responding to fathers and facilitating the novice to expert progression.

A substantial literature base exists in the Nursing and Healthcare fields regarding the transformation process of individuals experiencing life crisis (grave illness, family member death etc.) which is a similar process that parents experience after the birth of a child with a disability. This notion suggested that a difficult life experience, though stressful, could be a catalyst for change and significant growth in an individual or system i.e. transformation (Barnard, 1994; Janoff-Bulman,

1992). Scorgie, Wilgosh, and Sobsey (2004) offered a theoretical model of the transformation process as it applied to parents of children with disabilities, citing evidence from parent interviews that the experience of parenting a child with a disability resulted in positive changes for the parent. The Transformational Outcomes Model (Scorgie, et al., 2004) is a complex working model that described three key processes involved in parent transformation from novice to expert: image making, meaning making, and choice making. Each of these processes involve parents attempting to reconcile their expectations of parenthood with the reality. In the early period after diagnosis, a parent seeks to redefine the identity of their child and him/herself. Parents will also struggle to construct meaning of their reality by seeking to understand why their child has a disability and what the future holds for their family. Finally, the process of choice-making is required for transformational outcomes. Here, parents learn to manage daily life by considering options and responding to challenges. These processes are considered to be overlapping and possibly cyclic rather than separate and take place during the development of a bonding relationship between the parent and child. Scorgie, et al. (2004) offer that these three critical processes have the potential to result in personal growth, improved relationships, and evolution of philosophical and/or spiritual values. Gray (2015) stated this model is preferred because it allows the human services professional supporting the family to better understand what processes led the parent to a constructive and positive outcome.

Methods

According to Scorgie et al. (2004) and Pelchat et. al (2009) research was lacking in regards to the process of transformation following the diagnosis of a disability and more precisely, the voices of fathers. This qualitative study used a case study framework to understand the transformative experiences of two fathers who had children born with disabilities. Data was collected through an interview with the fathers.

Two fathers known to the researchers since the time of the children's diagnosis of disability participated in the study. These fathers have gradually come to be viewed as veterans in the local community and regularly participate in activities designed to bring a parent voice to human service professionals' pre and in-service education. Following approval from the institution's Internal Review Board, each father was contacted via telephone to inquire about their willingness to participate in a study related to their experiences as fathers of children with disabilities. After informed consent was obtained, both fathers participated in a joint 90 minute interview with the researchers. The interview was audiotaped and the researchers also took notes. The fathers were instructed to bring three to four pictures to assist in describing their journey from novice father to expert during the interview. In addition, the fathers were asked to identify words that they would use

to describe their diagnosis experience as well as words they would use to describe their experience at the present time.

Verbatim transcriptions were analyzed with NVivo© qualitative analysis software and the researchers held a number of meetings to review, analyze and interpret the data. The researchers utilized the approach recommended by Creswell (2013) and Miles and Huberman (1994) which begins with data organization followed by data coding and analysis and ends with data representation and interpretation. The researchers constructed themes from the codes which were refined until saturation was achieved.

Case Descriptions

Father 1. Father one is an educator working in an after school program. He is married to the mother of his two daughters, ages 11 and 3. Father 1's oldest child was born very prematurely and is deaf and visually impaired. His second daughter experienced a stroke at birth and has cerebral palsy. The family lives together.

Father 2. Father two is a businessman and is married to the mother of his six children. The family has three biological children, the third was born with Down Syndrome. The family has since adopted three children who also have Down Syndrome. The family lives together; their oldest adult child lives away from home but is highly involved.

Both families reside in rural states in the upper midwest.

Results

Two main themes emerged from the data analysis: laughter was a frequent emotion throughout the narrative and, both positive and negative emotions were identified throughout the transformation process. First, an analysis of the most frequently occurring word and/or audible emotive in the interview revealed laughter. Figure 1 illustrates the frequency tree generated by the NVivo© software. As they described various aspects of their transformative experiences, both fathers used laughter to express and enrich their verbal exchanges:

Father 1: "When my wife asked her, 'How was the campout with dad?', She said, 'Good, but daddy he sure sleeps loud!' When your deaf daughter can hear your snore, you know you have a problem (laughter)."

Father 1: "There was this time when we were working on the rhyme No More Monkeys Jumping on the Bed. (Child) and I made it into a live action game where I got on all fours on the bed and she got on my back and I launched her off. That game had to come to an end when I accidentally overshot and she face planted into the wall (laughter). Yeah, my wife put a stop to that (laughter)."

Father 2: "I'd like the record to reflect, I would choose the word experienced. Because expert-- in the last 24 hours, there have been two or three moments where I might not have looked like an expert (laughter)."

Father 2: "I'm pretty sure that a fair number of people close to us were somewhat concerned, but supportive when we said we'd like to adopt a little girl with Down Syndrome. -- I'm sure there are a lot of people with that, 'It's a good thing. It's nice of you to do that.' Then we said, 'Okay, we're going to have to be there for two months. It's going to be a significant amount of money, and a significant amount of unmarked \$100 bills that will exchange place in a location that will be not videoed, and not official, and no receipt.' I think we had a lot of people going, 'What are you doing (laughter)?', 'Why would you do this (laughter)?!'"

When asked to offer words that described them at the time of their child's diagnosis and at present, the father offered both positive and negative descriptors. Word clouds formed by the fathers' descriptors, including synonyms, are displayed in Figures 2 and 3. Examples of the fathers' mix of both positive and negative emotions include:

Father 1: "Yeah. I mean, it was a bad-- it was up and down. I think it was probably two and a half weeks after she was born, she contracted a virus. She wasn't going to the bathroom, so she was retaining all the of the fluid and she just kind of plumped up like a hot dog would on a grill."

Father 1: "I put joy, just because now 11 years later, if you've gotten to know her, she's just like any other 5th grade student. She plays the violin, she dances, she's convinced she's going to be a cheerleader when she gets in a high school."

Father 2: "But it was such a beautiful moment: we cried, we laughed. We went to the closet, and then, like now, we had four different sizes of pull-ups in the closet. And we said, 'I guess this is what it means to be a part of the sandwich generation (laughter)'. You got your mom's pull-ups and your three youngest kids' pull-ups, and you've got to make sure that they all have them on!"

Father 2: "This would be the picture of (child) as he comes running to me. With only seeing me on a picture, he ran right to me. It's my favorite video. We play it a lot, of him just coming to us, coming at me."

Figure 1. NVivo© Frequency Tree

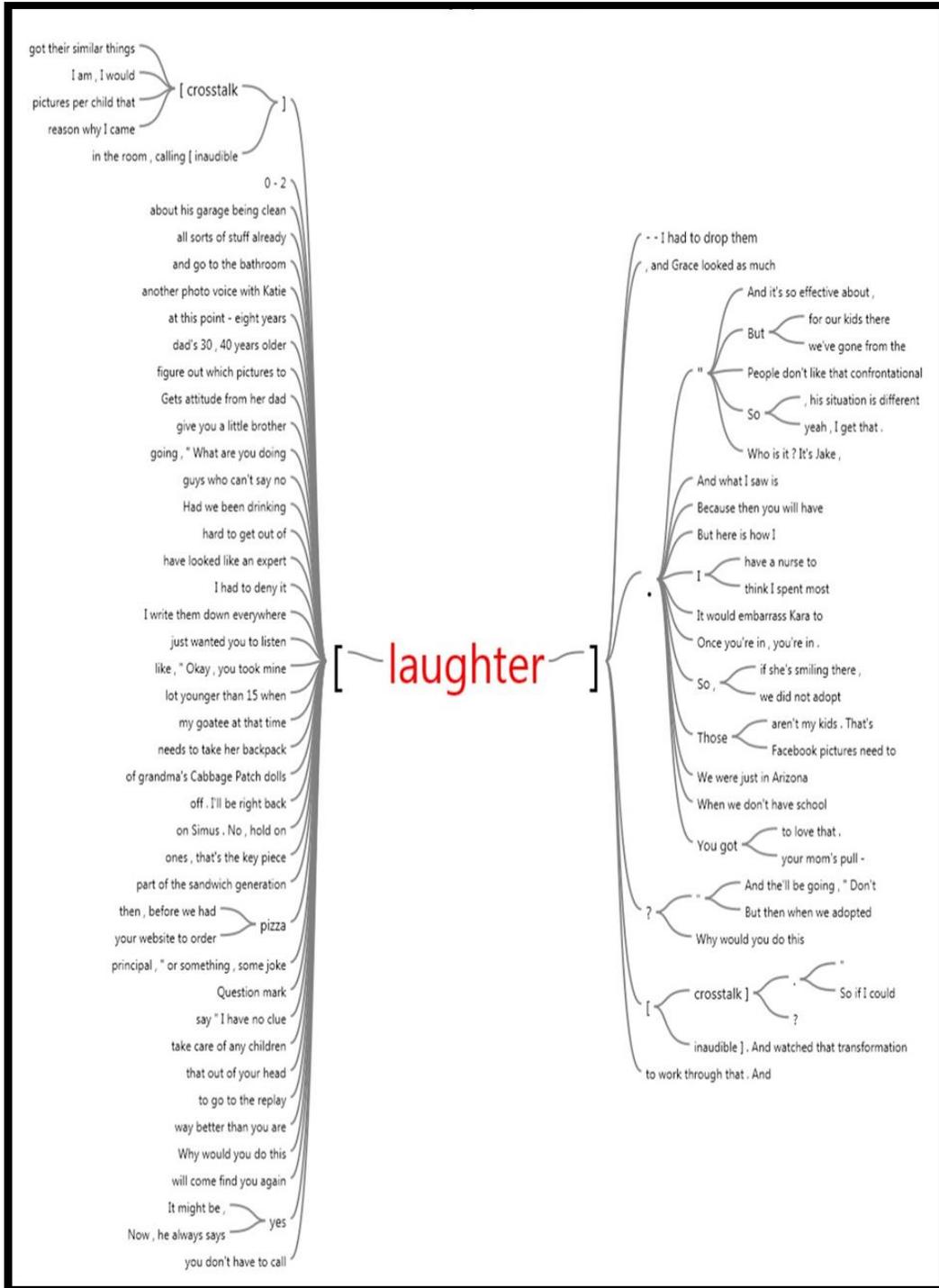


Figure 2. Fathers' Emotions at Diagnosis

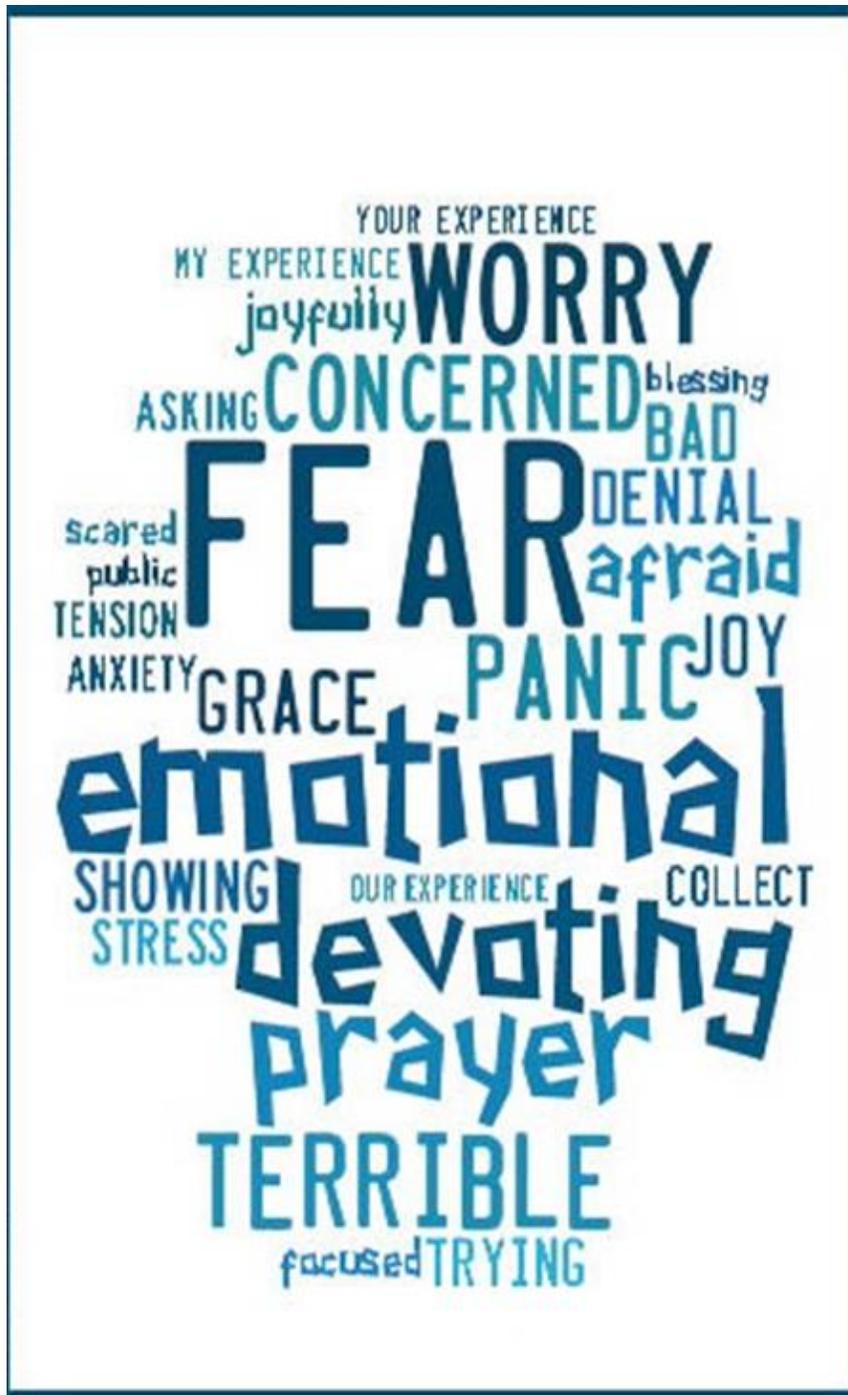
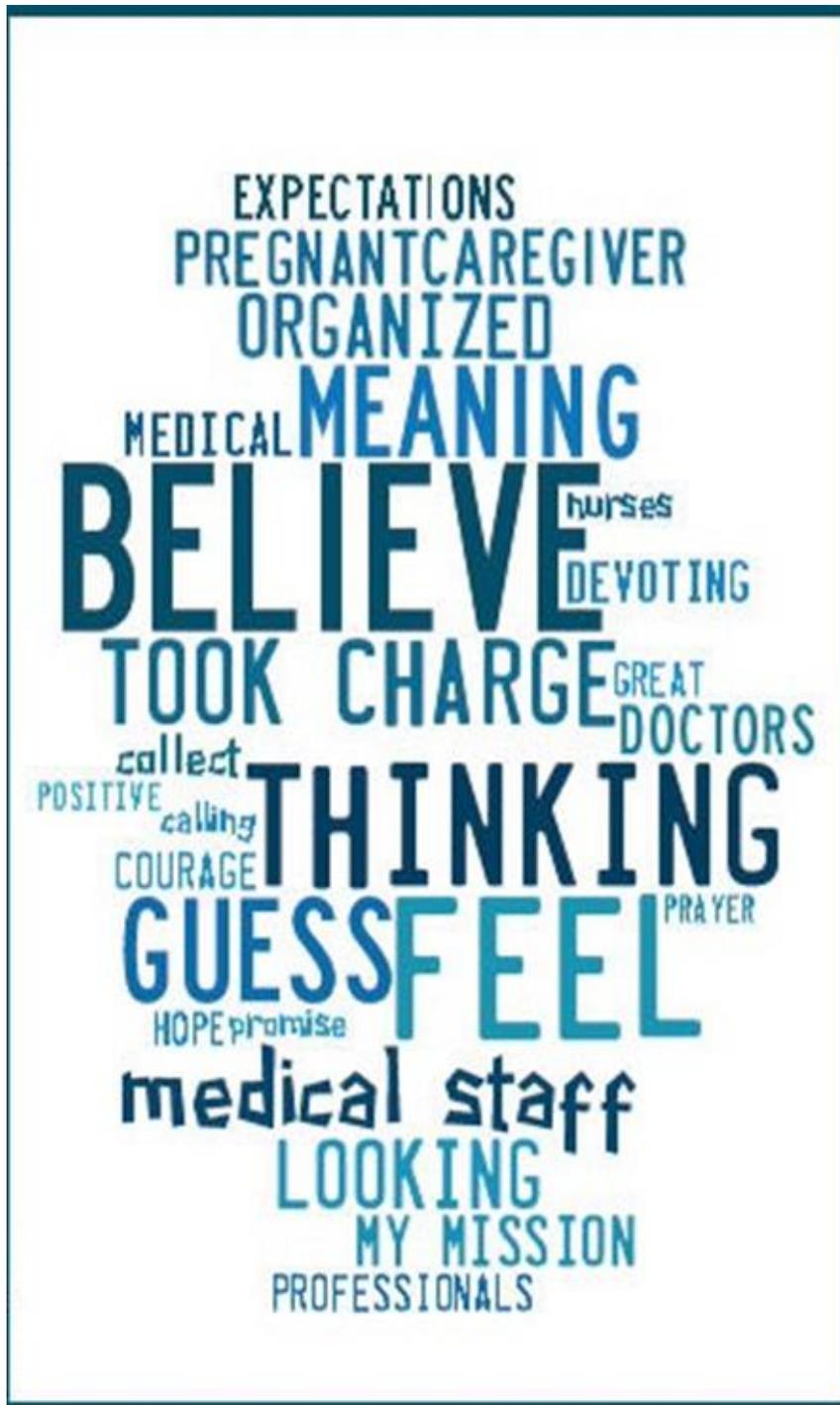


Figure 3. Fathers' Emotions at Present



Discussion

This initial analysis of the qualitative data identified two significant insights into how fathers of children with disabilities describe their transformation process: 1) laughter was a highly frequent occurrence, characterizing the tone of the fathers' discussion as they relayed their transformation process and 2) the fathers used a mix of both positive and negative words when describing themselves as a parent at the time of their child's diagnosis and at present.

Laughter

Is laughter the best medicine? This question was posed often in medical literature purporting the benefits of humor. Numerous popular press articles promote humor, laughter, and positive thinking as a coping strategy for everything from the stress of daily life to complex health crises. However, there was little research into the actual application of laughter in health care nor in disability related fields (Horowitz, 2009; Rieger & McGrail, 2015). While mothers have reported laughter and prayer as coping strategies for their children who experience a chronic health problem (Sampson, Parker, Cheezum, Lewis, O'Toole, Patton, Zuniga, Robins, & Keirns, 2013), the current study suggests that this is also true for fathers of children with disabilities.

Positive and Negative Emotions

These results supported recent findings (Myers, Mackintosh, & Goin-Kochel, 2009) acknowledging that parents might experience a mix of both positive and negative emotions throughout the life of their child with a disability. While fathers have traditionally been characterized as less emotional than mothers (Jansz, 2000) and less willing to share their emotional states (Sopcak, Mayan, & Skrypnek, 2015), the experienced fathers in this study were willing to discuss their varied and strong emotions related to parenting a child with a disability. This may suggest that the transformation experience is also facilitated by a father telling his story as a meaning making process leading to successful transformational outcomes in Scorgie, et al's (2004) model.

The display of laughter and positive emotions by fathers of children with disabilities, especially in the novice stages of fatherhood, may be interpreted by professionals as denial. The traditional model of the grief cycle as linear suggested negative emotions that parents should experience soon after the diagnosis of their child's disability (Kubler-Ross, 1969), indicating that the display of positive emotions and laughter may be somehow pathological. However, recent literature has challenged this assumption citing evidence that an individual may take unique and varied paths to transformation after a life-changing event (Bonanno, 2008). Counseling approaches that cultivate positive emotions and support the

development of coping strategies that lead to finding meaning may be appropriate for use with fathers of children with disabilities because they align with the Transformation Outcomes model (Scorgie, et al, 2004); however, more research is needed on how to operationalize such approaches for human service professionals working with this population. While laughter and positive emotions were used by the fathers of children with disabilities in this study as tools in the transformation process, the limitations of a case study as well as individual differences amongst fathers must be recognized. Humor and laughter can promote positive parent-professional relationships, but only if used carefully (Rieger & McGrail, 2015). The level of trust and relationship status between the provider and the parent will influence how and when to use laughter. Just as the role of fathers differs amongst culturally fathers, so does the use of laughter. Cultural sensitivity must be observed in such situations due to the risk of using laughter inappropriately.

Limitations

This research was a case study of two fathers' perceptions. Caution is warranted in making generalizations about the findings. The primary researcher has previously held the role of early intervention provide for both families, thus a previous relationship existed which may have increased the comfort level of the fathers during the interview. In addition, the secondary researcher has a child with a disability thus the fathers may have responded differently than they may have to a researcher without a shared experience. Due to these factors, the researchers brought some bias into the study which must be considered when interpreting the results and findings.

Conclusion

This study highlighted the importance of fathers as integral members of the family of a child with a disability. The findings clearly demonstrate that fathers are not only integral members but experience their own transformative processes. There is a great deal of research surrounding children with disabilities; yet, it continues to focus on mothers and be conducted primarily from a female professional standpoint (Carpenter & Towers, 2008; Ly & Goldberg, 2004). While this study concluded that fathers, too, must be included it also recommends that more research regarding fathers be sought in order to provide practitioners the appropriate resources to support families.

This study may be of great value to multiple practitioners including; nurses, doctors, social workers, early interventionists, and therapists. The first moment that a family, including fathers, are given a diagnosis of a disability are critical. Practitioners who model a tone of acceptance with positive emotions while acknowledging and honoring negative ones will not only be providing quality care to the families but also can positively impact the trajectory of the families journey.

While the study highlighted an ongoing element of laughter, it is important to recognize that not only is laughter multifaceted, laughter must be used with caution. According to Reiger and McGrail (2015) humor could be categorized into helpful or harmful styles related to family functioning. This is essential for practitioners to not only understand but be mindful of when working with families. This reveals the delicate balance of art and science when working with families. In addition, as previously indicated by Appelbaum and Smolowitz (2012), Carpenter and Towers (2008) and Ly and Goldberg (2014), the contributions of fathers was critical in the healthy functioning of the family as a whole.

This study concluded that laughter and the use of positive emotions, while honoring negative ones, may be a tool fathers of children with disabilities use in their transformation process. Positive and negative emotions can reside together and perhaps facilitate transformation. The experienced fathers in this case study demonstrated an ability to authentically and genuinely display the full range of emotions related to their experience. While laughter was utilized regularly the fathers did not minimize the difficulty that comes with parenting a child with a disability nor the challenges they have to face as a family. As Father 2 noted, “*Having children with disabilities does not ‘take a special family’; it makes a special family.*”

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