



Poster Presentation

Post-Traumatic Growth in Parents of Children With CHARGE Syndrome

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Presenter Information

Shelby Muhn is third-year School Psychology Doctoral student at Central Michigan University and a current member of the CHARGE Syndrome Research lab. In 2016, she received a Bachelor's of Science in Psychology from Central Michigan University with a minor in American Sign Language. She has been involved in the CHARGE Syndrome community now for shortly over three years. She is interested in the psycho-social well-being of parents of children with CHARGE Syndrome, as well as, mind-body interventions to promote the well-being of individuals with CHARGE Syndrome. She is currently studying the effects of a martial arts intervention, Fun Chi, for on-task behavior in classrooms. Her future research seeks to address mediating variables for Post-Traumatic Growth in parents of children with CHARGE Syndrome.

Tim Hartshorne is a professor of psychology, specialized in school psychology, at Central Michigan University. His doctoral degree is from the University of Texas at Austin. He also has a master's degree in counseling and is a licensed professional counselor. He is the grant holder for DeafBlind Central: Michigan's Training and Resource Project, which provides support to children who are deafblind in Michigan. Much of his work is influenced and motivated by his son Jacob, who was born in 1989 with CHARGE syndrome. Tim's particular interests include understanding the challenging behavior exhibited by many individuals with deafblindness, CHARGE, and related syndromes, and also how severe disability impacts the family. He is the lead developer of a deafblind intervener training module on behavior for the National Center on Deaf-Blindness. He has been awarded the Star in CHARGE by the CHARGE Syndrome Foundation. His research was recognized in 2009 with the Central Michigan University President's Award for Outstanding Research. He is a frequent presenter on CHARGE and deafblindness.

Presentation Abstract

Having a child with a severe disability such as CHARGE Syndrome can be a traumatic event for families. They may feel isolated, guilty, or discouraged as they experience significant challenges and face adversity. Although they face these encounters, many parents demonstrate considerable strength and growth, which is known as post-traumatic growth (PTG). A review of the literature on PTG in parents who have children with severe disabilities will be presented and experiences of having a child with a severe disability will be discussed. Lastly, a proposed research study is presented examining factors of belonging within the CHARGE Syndrome community and how engagement in the community may positively contribute to PTG.

Posttraumatic Growth in Parents of Children With Disabilities

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What Is Post Traumatic Growth?

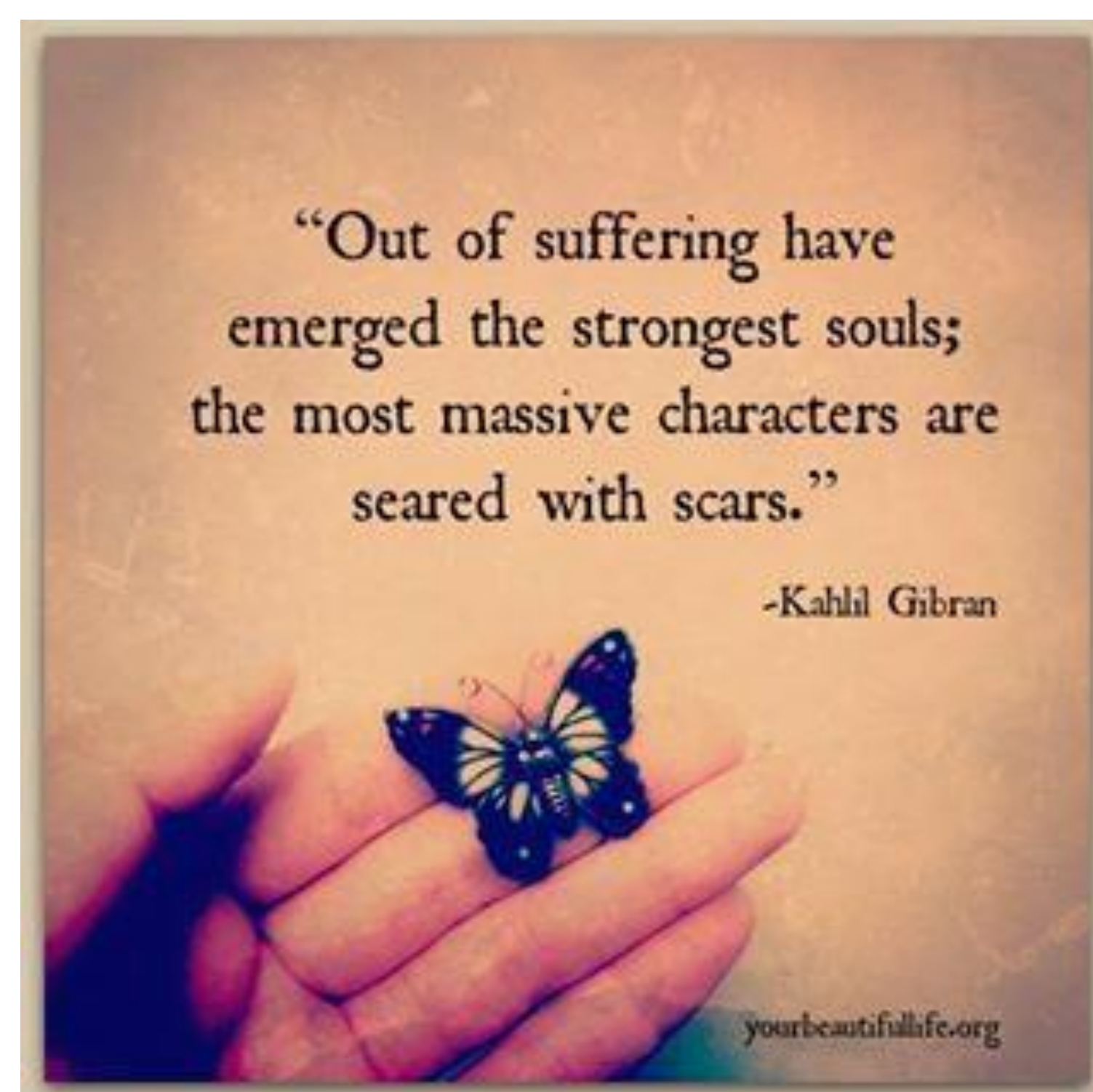
- A positive change experienced as a result of the struggle with a major life crisis or a traumatic event, and the idea that human beings can be changed by their encounters with life challenges, sometimes in radically positive ways, is known as posttraumatic growth (PTG).
- Tedeschi and Calhoun (2004) defined the phenomenon of demonstrating considerable strength, articulating the positive contributions of their child's disability as posttraumatic growth (PTG, 2013).

Five-domain models comprising PTG:

- New possibilities
- Appreciation of life
- Personal strength
- Relating to others
- Spiritual/religious change

(Tedeschi & Calhoun, 2004)

- Phelps et al. (2008) noted that Traumatic losses, such as the realization that your child will not develop typically, may lead parents to find new insights in life and develop a greater sense of spirituality and strength.



Why having a child with a disability can be traumatic

- The experience of raising a child with severe disabilities can be very isolating for parents.
- Group reunions are not what had been anticipated, and any gathering of friends with typical children is a troubling reminder of the differences.
- Friends quite naturally brag about the accomplishments of their children, playing sports, excelling at school. Sharing how your child reached out to you for the first time at 18 months, or managed to swallow some food at 24 months, or took a first hesitant step at five years seems to pale in comparison (Hartshorne & Hoesch, 2016).

People oo and ahh about my baby → People avoid looking at my baby
My baby is so advanced → My baby may never advance
My baby watches my every move → My baby does not look at me
My baby will be a doctor or lawyer → I hope that my baby lives
We are already considering preschool → Will any school take my baby?
My baby loves to be held → My baby avoids my touch

Experiences

- Although rearing a child with disabilities can place distress on mothers, evidence is coming to light that parents of children with disabilities demonstrate strength, expressing the positive contributions of their child's disability to their lives and well being (Bayat, 2007; Benson, 2010; King et al., 2006).
- Raising a child with severe disabilities allows for perspective changes, increased sensitivity, increased community support, more opportunities to learn, improved family dynamics, and increased assertiveness and strengthened spirituality (Taunt & Hastings, 2002).
- "Through working together, we all learned how to help my son. This in some sense made our family closer, because an individual cannot handle the toughness alone (Bayat, 2007)".

How to Facilitate Growth?

- Counselman-Carpenter (2016) found that mothers of children born with Down syndrome found new possibilities relating to others, specifically those who had similar experiences.
- Effective coping styles
 - Downward comparison
 - Problem focused coping
 - Self-efficacy
- The Posttraumatic Growth Inventory* (Tedeschi et al., 2017) used to evaluate the existence and extent of experiencing growth following traumatic experiences.
- Finzi-Dottan et al. (2011) proposed that information regarding results of the PTGI can identify positive responses and increase the ability for practitioners to promote psychological reframing for parents.



Transform suffering into positivity

- Phelps et al. (2009) found parents presented both high levels stress and high scores on the PTGI.
- This conveys that stress should not be denied but may serve as a trigger for the possibility of significant resilience.
- Growth comes in cycles and ongoing stress promotes inner strength resulting in posttraumatic growth.



Positives of having a child with a disability

- Pleasure in providing care
- Sense of accomplishment
- Strengthened family
- New sense of purpose
- New skills, abilities, even a career
- Increased personal confidence
- New social networks
- Changed perspective on life
- Making the most of everyday

Future Research Questions

- Do parents of children with CHARGE syndrome experience PTG?
- How does PTG in parents of children with CHARGE syndrome compare to other populations of parents?
- What is the relationship between posttraumatic growth and social interest?

References

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