Title: Examining Birth Stories on Social Media of Parents of Children with Down Syndrome

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Introduction: New parents often experience emotional and physical changes, leading to a high likelihood of parents experiencing mood disorders such as anxiety and depression (Ko et al., 2017). As many as one in eight women in the U.S. experience perinatal depression or anxiety (Fairbrother et al., 2016). This is especially true for parents of children with Down syndrome (Ds). They often exhibit higher rates of stress, depression, and anxiety (Miranda et al., 2015). This is because often these parents are not aware of the diagnosis before giving birth but receive it within the first 24-48 hours following (Hall, Bobrow & Marteau, 2000). These parents are expected to cope with the diagnosis with very little emotional support from people outside of family members (van der Veek, Kraaij & Garnefski, 2009). Although this is a common occurrence, there is a large lack of literature on the perinatal experiences of parents who have a child with Ds, and how those experiences impact their mental and emotional well-being. However, many of these parents are very active on social media and in advocacy networks, and often use these outlets to discuss their experiences of receiving a diagnosis.

Method: This study used a grounded theory qualitative analysis approach to examine social media posts by parents of Ds, specifically in which they posted stories about the birth of their child with Ds. The social media platforms Facebook, Twitter, and Google were searched for posts that used the hashtags #downsyndrome, #birthstory and #downsyndromebirthstory. Forty-three total stories were found (6 from Facebook, 13 from Twitter, 24 from Google) of individuals who specifically identify in their biographies as a parent of a child with Ds, and who were sharing either birth or prenatal stories of their child. These stories were extracted, de-identified, and then qualitatively coded using inductive open coding to determine emerging themes. These themes were visually represented and analyzed to determine final results and build the conceptual framework surrounding experiences of perinatal depression and anxiety of parents who have just received a Ds diagnosis for their child.

Results: The data from this study resulted in a conceptual framework describing the process that parents experience when discovering that their newborn child has Ds. A diagram of this process can be found in the figure below. There are five phases in this process: 1) whether or not any pre-screening indicators were present; 2) parents receiving confirmation of the diagnosis of Down syndrome; 3) parents immediate emotional reactions to hearing the diagnosis; 4) parents internal processing of the diagnosis; and 5) the mental health outcomes of parents experiences. Throughout these five phases there were also determined to be three factors that impacted the way that parents engaged in this process: 1) the role of the medical professional in discussing the diagnosis, 2) the support the parent receives from their partner; and 3) the support the parent receives from others around them (e.g. other family members).
Discussion: The conceptual framework that resulted from this exploration provides a unique look at the process that parents go through when receiving a Ds diagnosis for their new-born child. Although parents began and ended this process with excitement over having a child, they experience a more intense emotional process within the first 24-48 hours after the birth of their child. They also often leave this experience with a completely new identity as a parent of a child with Ds. By analysing their social media stories, we were able to examine how these parents viewed and described this process with other members of their online community of parents of children with Ds. These findings highlight the need for medical personnel to be aware of this unique transition and to help parents fully engage in this identity-changing process while they are still in the hospital receiving the diagnosis. The findings also exhibit the need to understand that perinatal depression and anxiety looks different for these parents because of their unique circumstances, and to help them engage in services accordingly.

References:


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