



Reframing Autism: Young Adults With Autism Share Their Strengths Through Photo-Stories

Michelle Teti DrPH^{a,*}, Nancy Cheak-Zamora PhD^a,
Bridget Lolli MPH, BSN, RN^b, Anna Maurer-Batjer BS^a

^aDepartment of Health Sciences, University of Missouri, MO

^bThompson Center for Autism & Neurodevelopmental Disorders, University of Missouri, MO

Received 25 January 2016; revised 1 July 2016; accepted 6 July 2016

Key words:

Autism;
Photovoice;
Qualitative;
Transitions;
Young adults

Purpose: A dearth of research describes the lives of young adults with autism spectrum disorder (ASD) from the perspectives of young adults themselves. We explored young adults' strengths using Photovoice, a method in which participants use images and discussions to express themselves. Images were purposefully chosen to help young people participate in the research process.

Design and Methods: Eleven young adults captured their experiences growing up with ASD via images, and participated in three group photo discussions, an individual photo interview, and a photo exhibit. Qualitative data for analysis included session transcripts and photographs. We used strategies of theme analysis to understand participants' experiences.

Results: The mean age of the sample was 20 years, and 7 participants were male. Three sub-themes describe youth's strengths: 1) special interests that cultivated positive emotions and coping strategies; 2) skills and activities that evoked pride; and 3) reframing ASD as special versus a disadvantage.

Conclusions: The Photovoice method is well-suited to help young adults identify and express their strengths. Self-generated images and stories may offer a creative and effective form of communication for young adults with ASD.

Practice Implications: Health care practitioners can capitalize on how Photovoice helps young adults express themselves by using images to understand their health priorities and involve young adults in their care plans. With images of strength, for example, nurses can build young adults' confidence and help these individuals to identify areas of their mental and physical lives in which they can thrive and experience improved quality of life.

© 2016 Elsevier Inc. All rights reserved.

From communication and behavioral difficulties to a plethora of troublesome comorbid medical conditions, narratives of the challenges facing young adults with autism spectrum disorder (ASD) abound in research, practice, and popular culture (Centers for Disease Control and Prevention, 2015). A critical yet understudied aspect of young adults' lives, however, is their strengths and talents (Autism Speaks,

2016). Pictures can support expression of strengths among young adults with ASD by offering an alternate form of communication to words alone, encouraging creativity, and providing a concrete symbol to facilitate their ideas (Autism Speaks, 2016). In this study, we chose images purposefully as a means to help young people express themselves more fully in the research process. We used Photovoice, a participatory research method in which people express themselves with images and discussions (Wang & Burris, 1997), to elicit young people's accounts of "growing up" and becoming an adult. This analysis focuses specifically on the

* Corresponding author: Michelle Teti, DrPH.

E-mail address: tetim@healthmissouri.edu.

strengths and resilience of young people with ASD, which was one of the key themes that emerged as important in young adults' depictions of this notoriously tumultuous life period.

Characteristics of ASD

Nurses and other healthcare providers are likely to encounter young adults with ASD in their practices (Inglese, 2009). ASD is a lifelong developmental disability that affects 1 in 68 children in the United States (Centers for Disease Control and Prevention, 2015). Although ASD is a spectrum disorder with symptoms varying across individuals and over time, the primary features of ASD include communication deficits, impaired social interactions, restricted interests, and repetitive behavior patterns (Centers for Disease Control and Prevention, 2015). Often as a consequence of these primary symptoms, young adults with ASD exhibit elevated risk for anxiety, depression, loneliness, and stressed social relationships – including bullying and victimization (Skokauskas & Gallagher, 2012; Zeedyk, Rodriguez, Tipton, Baker, & Blacher, 2014). In addition to their behavioral and communication difficulties, nearly half of those with ASD have a major coexisting medical condition, such as seizures, gastrointestinal problems, and/or sleep disturbance, requiring regular medical attention (Aldinger, Lane, Veenstra-VanderWeele, & Levitt, 2015; Kral, Eriksen, Souders, & Pinto-Martin, 2013; Levy et al., 2010).

The Strengths of Young Adults With ASD: A Research Gap

Given the range of social, psychological, and physical health challenges that young adults with ASD face, it is not surprising that much of the published research about them focuses on their deficits (McCrimmon & Montgomery, 2014). Assessing the clinical and often problematic aspects of ASD is important to improve the diagnostic process and enhance health care practitioners' understanding of ASD (Cheak-Zamora & Teti, 2015; Heidgerken, Geffken, Modi, & Frakey, 2005). Diagnostic and treatment needs are the focus of the health care system, with practitioners often working exclusively with caregivers to manage young adults' diagnostic and treatment needs (McCrimmon & Montgomery, 2014). However, young people with ASD are more than a collection of diagnoses and challenges. Many exhibit strengths or resiliency, which is the capacity to demonstrate and achieve positive outcomes despite adversity (Masten, 2001). Existing research describes resiliency among many diverse young adults, including those who have experienced violence, trauma, and poverty (Luthar & Cicchetti, 2000). Health researchers and practitioners with expertise in ASD acknowledge the importance of resilience as a lens to guide research and practice so that it fosters young adults' strengths instead of highlighting their difficulties (McCrimmon & Montgomery, 2014). Actual strength-based research and practice for young adults with ASD

trail behind the calls for such perspectives (Giarelli, Ruttenberg, & Segal, 2013; McCrimmon & Montgomery, 2014).

The little strength-based research that does exist focuses mostly on caregivers of young adults rather than the young people themselves, describing predictors of caregiver qualities that support positive outcomes among families with young adults with ASD (Bayat, 2007; Bekhet, Johnson, & Zauszniewski, 2012a, 2012b). A small amount of research also describes the preliminary potential of strength-framed education and skills programs for young adults – like video self-modeling to enhance confidence and success in daily tasks and positively oriented problem-solving interventions (Aduen, Rich, Sanchez, O'Brien, & Alvord, 2014; Bellinia & McConnella, 2010). Finally, Montgomery et al., (2008) explored the relationship between resilience and emotional intelligence (i.e., understanding self-emotions, understanding other's emotions) in young adults with ASD, finding a relationship between the traits (Montgomery et al., 2008). To our knowledge, no other research about young adults with ASD and their strengths exists.

Photovoice to Support Young Adults' Expression

Photovoice invites participants to take pictures to describe their health (Wang & Burris, 1997) and then to share the pictures with others. The theoretical basis of Photovoice includes three related concepts: empowerment education for critical consciousness; feminist theory; and documentary photography. These foundations share common assumptions about the importance of participants' voices (Wang & Burris, 1994). Through focusing on and portraying participants' experiences, Photovoice empowers individuals to understand and critically discuss the contextual issues that affect their health and well-being. This approach enables participants to communicate their concerns/needs/vision to their peers, families, and to those with authority to allocate resources towards meeting those needs (Wang & Burris, 1994, 1997). In fact, early versions of Photovoice have focused almost exclusively on helping participants to use their pictures to advocate for specific social action or policy change (Wang & Burris, 1994, 1997). From a feminist approach, then, Photovoice promotes the value of unrepresented groups' experiences and fosters a climate in which underrepresented groups are able to influence knowledge or action among others via their input (Wang & Burris, 1994, 1997). Further, when participants act as documentary photographers and record their lived experiences, they are "often imaginative and observant" in ways that provide more richness to the data than researchers could generate without this kind of participant input (Wang & Burris, 1994, p. 177).

Photovoice has been used extensively in public health among racial/ethnic minority communities, people living with HIV, young mothers, people in poverty, and those suffering from mental illness, among other populations (Catalani & Minkler, 2010). Photovoice has been used sparingly with people with ASD (Obrusnikova & Cavalier, 2011). The extensive literature on the value of Photovoice

Download English Version:

<https://daneshyari.com/en/article/5570072>

Download Persian Version:

<https://daneshyari.com/article/5570072>

[Daneshyari.com](https://daneshyari.com)