FINDING MEANING IN LIFE FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: A SALUTOGENIC APPROACH

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Abstract

Parenting a child with autism spectrum disorder (ASD) has never been easy. Research has shown that parenting stress is much higher whose children are diagnosed with developmental disabilities such as ASD than typically developing children. The contributing factors include, but not limited to, the child's limited social and communication skills and restricted and stereotypical activities (core deficits of autism). Parents lacking knowledge about ASD often resort to other forms of interventions in the hope to find a cure and believe it can help to eradicate the deficits of the disorder. Such treatments are known as complementary and/or alternative medicine and are not evidence-based. As there is no current remedy for ASD, perhaps it is time for parents to stop finding a cure to this disorder. In this paper, the author uses the application of the theory of salutogenesis and with the use of the three salutogenic components – meaningfulness, comprehensibility and manageability, aim to help parents establish a sense of coherence by identifying, understanding and managing their children with ASD.

Keywords: autism spectrum disorder, children, salutogenesis, sense of coherence

Introduction

The world seems to come to an end when parents know that their children are diagnosed with autism spectrum disorder (ASD). They are often helpless and highly stressed upon receiving the diagnosis. Their current dreams in life seem to vanish instantly when they come to know about this hard truth. Most of them still cannot accept the fact that their child is autistic and remain in a stage of denial for a period of time. As for some parents, they tend to accept that this is a true fact and hence, they

started to read and gather as much information as possible on autism, either online or from books, on how best to help their child cope with ASD.

Autism is a lifelong neurological disorder characterized by a triad of impairments, which usually include communication (verbal and non-verbal), social interaction, and repetitive and stereotyped patterns of behaviour (Pierangelo & Giuliani, 2007). According to the Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-V), a collective term known as Pervasive Developmental Disorders (PDD), is used as to include autistic disorder while Asperger's Syndrome, Fragile-X Syndrome, Rett's Syndrome, Childhood Disintegrative Disorder and PDD-Not Otherwise Specified (PDD-NOS) are the non-autistic PDD (American Psychiatric Association, 2013). However, Asperger's Syndrome is no longer under the classification of ASD under the DSM-V.

According to Pierangelo & Giuliani (2007), the age onset of ASD usually appears within the first three years of the child and the prevailing characteristics will be more obvious until the child reaches toddlerhood. Behaviours such as aggression (hitting, kicking, and biting), tantrums, and self-injury are not in the diagnostic criteria for ASD, rather they are secondary symptoms that develop when primary symptoms are not being addressed (Koegel, Koegel, Ashbaugh, & Bradshaw, 2014)

Globally, the prevalence rate of ASD is estimated to be 60 per 10,000 across all cultures. The diagnosis is higher for boys than girls with a ratio of 4:1. Recently, the prevalence rate in the United States is about 1 in 110 children diagnosed with autism and about 1 in 100 children in the United Kingdom (Chia, 2012). In Singapore, the number of children diagnosed with ASD has also gone up in the last decade with 361 ASD cases reported in 2005 and it went up to 528 ASD cases in 2010 (The Strait Times, 2012). A recent finding from Singapore government hospitals between 2003 and 2004 indicated that the most common clinical development diagnosis among young children is autism (Lian et al., 2012).

Most parents send their child with ASD for early intervention services and other private therapies such as speech therapy and occupational therapy. However, there are others who tend to seek other form of interventions in the hope to find a "cure" of the disorder. Such treatments are known as complementary and/or alternative medicine (CAM), otherwise known as integrative medicine. CAM includes, but not limited to,

nutritional supplements (e.g., injection of vitamin B12), diet therapy (e.g., casein-and-gluten free diet), and chelation therapy. Parents hope that seeking CAM can eradicate the characteristics of their child's learning disabilities. A recent article by Chua (2015b) advised parents who opted for CAM, such as going on a special diet or vitamin-supplement treatment to seek professional advice before administering any form of therapy to their child. Parents should consult a qualified medical doctor for any possible potential side effects should interventions involve psychotropic treatment.

Parenting a Child with ASD

Parenting a child is never easy, let alone one who is diagnosed with autism. For a child who is more severe on the autism spectrum and is unable to communicate his/her needs appropriately, parents find it difficult to interact with the child. In addition, when the child is unable to integrate or modulate his senses, he/she might display challenging behaviours such as incessant screaming and/or self-injurious behaviours (hitting, biting, or scratching). Apart from their daily work schedule, parents often feel highly stressed when they have to manage such behaviours of their child. Numerous studies has been done in the past to examine parental stress of children with ASD (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Brobst, Clopton, & Hendrick, 2009; Hastings, Kovshoff, Brown, Ward, Espinosa, & Reminton, 2005; Ornstein Davis & Carter, 2008; Tehee, Honan, & Hevey, 2009). Results showed that parents generally reported higher level of stress when rearing a child with ASD than parents with typically developing children (Baker-Ericzen et al., 2005; Hastings et al., 2005; Tomanik, Harris, & Hawkins, 2004). Factors causing high parental stress when rearing a child with ASD are many. A recent paper by Chua (2015a) stated several possible contributing factors that caused high parenting stress when rearing children with autism: (1) child's behavioural problems, (2) child's social interaction, and (3) child's autism severity.

Though stressed over their child's core deficits of autism and the future educational pathway, some parents adopt a different perspective on coping with issues on interventions, parental involvement, and the child's future employability challenges. Generally, most parents in Singapore would love to send their child to mainstream schools where they receive a formal education. There are some parents who do not want their child to be labelled as "autistic" and, hence place their child into mainstream school. Such parents are still in the denial stage and they strongly believed that their child would be "cured" from autism by placing their child into mainstream schools.

However, some parents are willing to place their child in special schools to receive therapy services where vocational skills are taught to prepare them for open employment in future. Usually, these parents have already surpassed the stage of denial as they had learnt to accept the diagnosis of their child and decided to move on in life. Their priority now is to help their child cope with their learning needs and challenges in order to integrate with the community.

The intent of this paper is to apply the theory of salutogenesis using the three salutogenic components – meaningfulness, comprehensibility and manageability. This approach aims to help parents establish a sense of coherence by identifying, understanding and managing their children with ASD, with the aim to find meaning in life, both to themselves and to their child.

What is Salutogenesis

The term *salutogenesis* derives from the Greek word of *salus* (meaning health) and *genesis* (meaning origin). Hence, the entire meaning of the term simply means the origin of health. First presented by Aaron Antonovsky in 1979, the salutogenic theory focussed on research in the area of health, stress and coping. His insights on salutogenic started when he conducted an epidemiological study on Israeli women born in Central Europe between 1914 and 1923 having menopausal problems. Among these were also women who had survived the cruel concentration camps of World War II. Having experienced severe stress and trauma, these women surprisingly had the ability to lead a good life and maintain good health (Antonovsky, 1987).

Antonovsky also introduced the term known as "Sense of Coherence" (SOC) to view the world and the individual environment as being comprehensible, manageable and meaningful (Antonovsky 1979, 1987). The theory of SOC explains why people are able to cope well by managing different kinds of life stressors and their health improve despite in stressful situations (e.g., financial downturn, loss of loved ones, and death). To Antonovsky, these "stressors" are not negatively valued after all and will contribute to nuances and meaning in life (Antonovsky 1979). In other words, he focussed on the strength and determinants of health. According to Antonovsky (1987), sense of coherence is defined as:

> *"a global orientation that expresses the extent to which one has a pervasive, enduring, though dynamic feeling of confidence that (1) the stimuli from one´s internal and*

external environments in the course of living is structured, predictable and explicable; (2) the recourses available to one meet the demands posted by these stimuli; (3) these demands are challenges, worthy of investment and engagement"
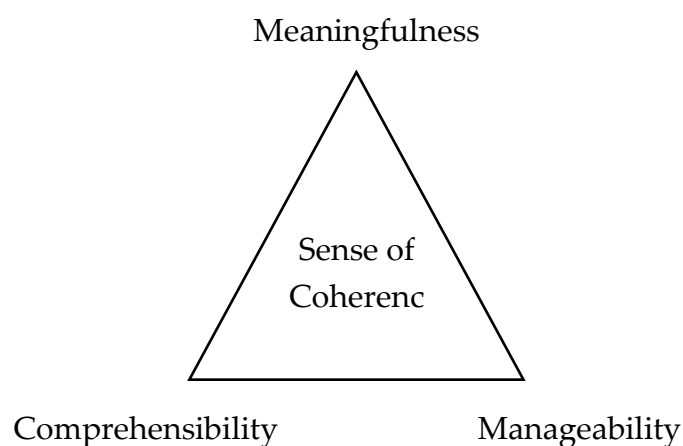
(Antonovsky, 1987, p.19).

The three dimensions of SOC are meaningful, comprehensible and manageable. This means that the more individuals understand the world they live in (how they perceive their existence as meaningful, comprehensible and manageable), the more they can utilise the resources they have within themselves and in their environment to maintain and develop their own health.

Instead of focussing on the aetiology of disease, Antonovsky's work turned this conventional question upside down and focus on the explanations for health: How do people cope to maintain and develop their health, and what predictive factors make this positive process possible? This is why the theory of salutogenesis is developed in order to answer these questions. He believed that diseases and stress happen all the time and concluded that chaos and stress is part of human life (Antonovsky 1991). To him, the important question is what causes health (salutogenesis), and not what the reasons for disease (pathogenesis).

Components of Salutogenesis

As mentioned above, the three components of sense of coherence are: (1) Meaningfulness, (2) Comprehensibility, and (3) Manageability as shown in Figure 1 below.

1st Component - Meaningfulness

According to Antonovsky (1987, p. 18), he considers meaningfulness as:

> *"...the importance of being involved as a participant in the process shaping one's destiny as well as one's daily experience. But was not until the interview protocols were studied that the significance of this component became apparent. I now see it as representing the motivational element. Those classified as having a strong SOC always spoke of areas of life that were important to them, that they very much cared about, that "made sense" to them in the emotional and not only the cognitive meaning of the term "*

Parents need to realise that there are certain things that they cannot change in life. Completely removing autism from their children is impossible as ASD is a lifelong neurodevelopmental disorder affecting areas of social interaction and communication. This is a true fact and parents need to come to an acceptance once a formal diagnosis has been given by the professionals. Denial is a natural process for most of the parents when they realised that their child has autism. It definitely takes time for them to accept the facts that they need to move on in life by helping their child to cope with the deficits of the disorder.

There are many ways in which parents can find meaning in life. For some, they cast their life challenges in religion, believing that the divine God knows what is best for them. In this way, they have a more positive outlook in life and bring this belief to their child with ASD with the hope of seeing more significant results of the child. As for parents without any religion, their meaning in life could also arise from seeing positive and significant improvement in their child's well-being through therapy lessons. The positive belief, or the "right belief" is crucial as it can impact on themselves, their children, and others. According to Feuerstein, Feuerstein, and Falik (2010) in the research on neuroplasticity, the human brain is capable for any minute changes that can adversely impact one's own behaviour and, ultimately affecting others as well. They conclude that new neurons can be grown and the human brain can be "trained" even into old age (Draganski, Gaser, Busch, Schuierer, Bogdahn, & May, 2004). Such findings imply that children with autism, who are provided with appropriate learning experiences from adult's positive belief, may develop abilities in their strength that may compensate for their weaknesses. For instance, if they lack the ability to remain on seat and perform tasks, intensive structured teaching, adults' modelling and repeated

training to stay on seat to perform meaningful activities will definitely help them to develop the ability over time as the neural connections develops.

One therapy that parents can make sense of meaning in life is to understand "*Logotherapy*". Founded by Viktor Frankl (1905-1997), an Austrian neurologist and psychiatrist, logotherapy (or Existential Analysis) dates back as far as 1930s. Logotherapy is derived from l*ogos*, a Greek word which means "meaning." While therapy is being defined as treatment of a disorder, sickness or maladjustment, Frankl's theory is based on the belief that human nature is motivated by the search for a purpose in life. There are three philosophical and psychological concepts of logotherapy: (1) life has meaning under all circumstances, (2) people have a will to meaning, and (3) people have freedom under all circumstances to activate the will to meaning and to find meaning for themselves.

Lately, logotherapy has been redefined by DeVille and DeVille (2010) as: "the synthesis of existential psychology and metaphysical philosophy that is pleasurable, powerful and permanent enough to sustain your life along lines of excellence in good times and bad" (p.1). In other words, Logotherapy is seen as a psycho-spiritual system relating to the human motivational pyramid to combine the physical, psychological and philosophical drives of life (DeVille 2009; Deville & Deville, 2010). While Frankl (1905-1997) focused on one's yearning for meaning in life, DeVille and DeVille (2010) have added the longing for belonging with people whom we share faith, hope and love, combining the focus of Logotherapy on personal meaning with their emphasis on situations and relationships where one belongs emotionally, is accepted, loved and trusted in places of the heart.

2ⁿᵈ Component - Comprehensibility

This second component of SOC is being explained as:

> "It refers to the extent to which one perceives the stimuli that confront one, deriving from the internal and external environments, as making cognitive sense, as information that is ordered, consistent, structured, and clear, rather than as noise-chaotic, disordered, random, accidental, inexplicable
>
> (Antonovsky, 1987, p. 17)

The above explanation can be further explained as individuals understand that facing obstacles are inevitable and that that there is a hidden meaning behind it and this is only possible if their SOC is strong (Antonovsky, 1996). Individuals with high sense of comprehensibility expect that the stimuli he or she will encounter in the future will be predictable and that they will be orderable and understood when they come as surprises (Kee & Chia, 2011). In other words, people with higher sense of comprehensibility can make sense of their current situation and has the confidence of making sense of future situations. In the field of health promotion, research on patients with back surgery, myocardial infarctions and cancer has shown that people who have higher SOC will lead to high comprehensibility as it provides them a basis to handle life better after major life events happened to them (Santavirta, Bjorvel, Konttinen, Soloviva, Poussa, & Santavirta, 1996; Tishelman, Taube, & Sachs, 1991; Viikari-Juntura, Vuori, Silverstein, Kalimo, Kuosma, & Videman, 1991). People having a strong SOC may protect themselves against depression, improves life satisfaction, and is linked with reduced fatigue, loneliness, and anxiety (George, 1999).

When a child is first diagnosed with ASD, parents may have no idea of what the disorder is. Gradually, they started to find out more from books, internet, friends whose child has autism, so as to learn and understand the disorder better. Some even attended conferences, seminars, workshops, and courses to find out more information on how best to help their child cope with the impairments of ASD. Day by day, they gradually build their knowledge and understanding of ASD. Once parents have already made sense of ASD and how best to work with their children, they are ready to face any challenges that comes to them in a comprehensible way.

3rd Component - Manageability

According to Antonovsky (1987, p. 17), he defines manageability as:

> *"… the extent to which one perceives that resources are at one's disposal which are adequate to meet the demands posed by the stimuli that bombard one. At one's disposal may refer to resources under one's own control or to resources controlled by legitimate others-one's spouse, friends, colleagues, God, history, the party leader, a physician – whom one feels one can count on, whom one trusts. To the extent that one has a high sense of manageability, one will not feel victimized by events or feel that life treats one unfairly. Untoward things do happen in life, but when they do occur, one will be able to cope and not grieve endlessly. "*

One of the challenges that parents have to deal with is the challenging behaviours of the child with ASD. Inappropriate actions such as excessive screaming, head banging, scratching, biting, and meltdowns in certain environments are some of the observable behaviours in children with ASD. They have problems in integrating or modulating their senses, or better known as sensory processing disorder or sensory modulation disorder. It is advisable for parents to have a good understanding of the "Culture of Autism". To gain a better understanding, Mesibov, Shea, and Schopler (2004) has helped educators and parents to create a conducive and positive learning environment which probably averted challenging behaviours. A structured environment where predictability and familiarity using a "Work System" such as the TEACCH program (Treatment and Education of Autistic and Communication Handicapped Children) has proven to be effective for helping children to address the core deficits of ASD (Mesibov, Shea, & Schopler, 2004).

Parents should also be well informed that autism is a multifaceted issue and there is no known cure currently. It is hoped that parents can focussed on the *management* on ASD, and not on the treatment per se. There is a distinction between autism treatment and autism management. According to Chua (2015b), treatment refers to a specific effort and remediating strategy utilised to improve the learning and/or behaviour of someone with autism, management refers to efforts to help someone with autism cope with his/her learning and/or behavioural challenges, but not necessarily to improve his/her learning or behaviour.

When parents possess the knowledge and ability to manage challenging behaviours of their children, understand the culture of ASD and find meaning in life (both theirs and the child), only then it will ultimately lead to perceived self-efficacy. This "refers to beliefs in one's capabilities to organize and execute the courses of action required to produce given attainments." (Bandura, 1997, p.3). This can only be achieved with better informed choices, obtaining available and relevant support services, through ongoing parental interactions with professionals (special education teachers, occupational therapists, speech and language therapists, and psychologists) and also their accumulated experience raising a child with special needs. In this way, parents are now able to make informed decision on what is best to be done for the benefits of their child.

Another area that parents can learn to manage their own social-emotional issues is to find an avenue to address their questions pertaining to raising children with autism. In

Singapore, there are parents who come together and share their stories, be it a success or failure during their parenting journey with their children. Focus group discussions, workshops, seminars, and online forum discussion are all available for parents to seek assistance. For example, a local hospital provides a platform called Caring and Sharing Parents Ever Resilient (CASPER) Parent Support Group where a group of parents whose children are on the follow-up at Kandang Kerbau Women's and Children's Hospital-Department of Child Development. The objective of CASPER is to provide a platform for parents to come together to care for and share with one another in their journey in parenting their children with learning disabilities.

Conclusion

The application of the theory of salutogenesis and its three components (i.e., meaningfulness, comprehensibility, and manageability) provides a perspective to help parents cope during their parenting journey of their children with autism spectrum disorder. Most importantly, parents who adopt the perspective of salutogenesis will help them construct coherent life experiences by having the ability to successfully manage the infinite number of stressors that occurred in the discourse of their life. It also enables parents to manage tension (manageability), to identify and utilise their available resources and supports (comprehensibility), and to promote effective coping by finding solutions (meaningfulness). In this way, the salutogenic perspective guides parents to find hope and meaning in life during their parenting journey for themselves as well as their child with autism.

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