

Reducing Uncertainty through Virtual Communities: Parents' Seeking Information for ASD Children in Indonesia

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ABSTRACT: Handling children with autism or Autism Spectrum Disorder (ASD) is not easy. Indonesian parents often feel worried and urgently need social support from the environment. Social support becomes important so that they could exchange information and reduce uncertainty about the future of their children. The rise of virtual communities has concrete implications for parents of ASD children in Indonesia. Through virtual communities, especially on social media such as Facebook, they can communicate each other and learn so much information about handling of their ASD children. It breaks distance and time constraints. This study aims to identify information seeking behavior of parents with ASD children through virtual communities. The research used qualitative approach, with virtual ethnography method. Data collection techniques were carried out through participant observation on Facebook LRD Member SuarAutisme by researching 178 uploads and 3,569 comments during August 2018 and in-depth interviews with the admin. The data encoded with NVivo 12 Pro. Result showed that to reduce uncertainty, parents of ASD children exchange information by 1) asking the admin about an issue 2) asking other members about an issue 3) exchanging experiences between members and admin 4) seeking reinforcement and emotional support 5) giving reinforcement and emotional support from member to other member 6) giving information and reinforcement from admin to member.

KEYWORDS: *ASD children, Facebook, parents, uncertainty reduction, virtual community*

I. INTRODUCTION

The number of children with Autism Spectrum Disorder (ASD) is increasing rapidly all over the world. Center for Disease Control and Prevention through Autism and Developmental Disabilities Monitoring (ADDM) stated that the prevalence among children aged 8 years in multiple U.S. communities have increased from approximately one in 150 children during 2000–2002 to one in 68 during 2010–2012, which the increase has doubled compared to previous years. For 2014, the overall prevalence of ASD was one in 59 children aged 8 years [1]. Meanwhile, there is no obvious data of ASD children numbers in Indonesia. But, it was estimated that 4 million people suffer from autism in Indonesia [2].

According to WHO, ASD refers to a range of conditions characterized by some degree of impaired social behavior, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out repetitively [3]. Children with ASD needs specific and complex intervention since they often experience intellectual impairment, seizures, and some of disorders such as digestive, sleep, and sensory disorders as well as concentration and behavior disorder. This situation brings parents of ASD children in an uncertainty condition. They often feel stressed thinking of their children, especially on how they should handle their children. Many researchers were reported that parents of ASD children had a higher stress level than parents with other disabilities. Ericzen, et.al, 2005; Lee, 2009 found that parents of ASD children have higher levels of stress than parents of typical children [4]. In Jordan, a research stated that parents of ASD children had greater stress than parents of Down syndrome children. Even the differences in level of stress were not significant between parents of children with Down syndrome and those with typically developed children [5]. In Japan, mothers of ASD children experience much greater parenting stress than mothers of typically developing children and children with other disabilities. Japanese mothers also indicate stress related to attachment difficulties, low parenting efficacy and lack of support [6].

This situation makes parents try to find information about handling ASD children. Join virtual community becomes an alternative way to access the information. It is important to them to reduce uncertainty about the condition and treatment for their children. Besides, various studies indicated that virtual communities provide social support for parents in handling ASD children. Computer devices through cyberspace are also reported to have a variety of positive implications on autism sufferers as well as parents of ASD children [7]. The rise of virtual communities has concrete implications for parents of ASD children in Indonesia. Through virtual communities, especially on social media such as Facebook, they can communicate each other and learn so much information about handling of their ASD children in order to reduce uncertainty. This study aims to identify information seeking behavior of parents with ASD children through virtual communities.

II. UNCERTAINTY REDUCTION THEORY

The Uncertainty Reduction Theory (URT) theory was originally created to explain the communication process that occurs when two strangers interact. Charles Berger and Richard Calabrese observed that when someone interacts with strangers, they experience uncertainty because they do not really know what other people expect. Berger and Calabrese claim that as the interaction continues, someone obtains information that quickly reduces uncertainty[8]. URT provides an explanation for these and other behaviors when people interact with new people. URT is related to interpersonal communication. In reducing uncertainty when interacting, someone will try to find information. When drawn in chart form, URT can be seen as follows:



Figure 1. URT Visualization

According to Brashers(2001) uncertainty occurs when the details of the situation are ambiguous, complex, unpredictable or probabilistic; when information is not available or is inconsistent; and when people feel insecure in their own knowledge or state of knowledge in general. Some experts argue that humans are consistently motivated to reduce uncertainty, while others say that there are situations where there is a desire to maintain, or even increase uncertainty. In the context of health communication, Brashers (2001) outlines and expands theories about uncertainty management. In the health context, medical decision making related to conditions where there is uncertainty is common (Babrow, et.al, 1998; Hines, 2001; R.C. Fox, 1998, 2000) in Brashers (2001). Both health care providers and patients, they experienced complexity and ambiguity in decisions about diagnosis and treatment options (Mishel, 1988, 1990) [9].

Still according to Brashers (2001) in UMT there is an opinion that patients will evaluate uncertainty as negative (produce anxiety, stress or distress), positive (related to opportunity, hope or optimism), or neutral (see uncertainty only as a "fact of life"). It depends on how a person evaluates the situation, where he will try to reduce, maintain or increase uncertainty. Patients can avoid obtaining information if they feel themselves ineligible to understand medical information, feel the need to submit to the health provider authority, or simply do not believe that information seeking will help manage their care.

In line with this, research on uncertainty in vaccine controversy as a cause of autism[10] stated that balanced reporting in the wrong newspaper relating to autism-vaccine controversy (AVC) increases the uncertainty of readers from the internal and external side with regard to vaccine relationships with autism. Specifically, readers of articles that report vaccines in a balanced but wrong way are more likely to see that there are relevant actors who share their opinions about the relationship of vaccines with autism, which in turn lowers their perception of certainty. Thus, it can be said that information seeking behavior to reduce uncertainty does not necessarily end up in finding certainty as described in the results of research.

Meanwhile research on information seeking related to uncertainty about skin cancer through websites[11] stated that there was a relationship between uncertainty and intensity of assessment. The intensity of the assessment will lead someone to search for information in more depth. In Berger's (2001) concept of Uncertainty Management Theory (UMT), a person will assess uncertainty as a potential hazard, or vice versa, providing potential in the form of benefits. This assessment is associated with emotional responses. Emotional assessments and responses motivated psychological behaviors and actions intended to manage this uncertainty[8].

Other research that looks for the relationship between uncertainty and affective reactions in individuals (such as anxiety and anger) in the context of environmental health risks reveals that, threats that are believed to exist in future generations, personal control and trust in government affect uncertainty, which will have an impact on dissatisfaction information. Another finding is that the more anxious and angry someone is about a risk, the more trust the risk is as uncertainty [12].

III. METHOD

This research used a qualitative approach, while the method was virtual ethnography. Kozinets in (Nasrullah, 2017) stated that virtual ethnography is a qualitative research methodology that is adapted from ethnographic research techniques to study artifacts, such as culture and community. The existence of the internet and its devices as well as computer-mediated communication (computer-mediated communications) became the field of study of this method [13].

The subject to be studied was a virtual community of parents who have ASD children. From the several virtual communities in Indonesia that exist on Facebook, the most qualified to be researched is **LRD Member SuarAutisme**. The reason for selecting this community was because it had the highest number of members (9,296 members, data as of May 13, 2019), the variety topics of discussion about autism, traffic of virtual community members is relevant to the substance of the research problem, and high number of posts from community members.

In this study the data collection procedure was participant observation in the closed group of LRD Member SuarAutisme. The research method used virtual ethnography, where one of the data collection was obtained from observations of texts produced by community members. Content analysis of text was performed on uploads throughout August 2018 with 178 posts and 3,569 comments. In addition, data collection was done through in-depth interviews with one of the administrators and founder of LRD Member SuarAutisme.

Coding was performed by the use of NVivo 12 Pro, in order to facilitate the content analysis represented in the form of nodes. Nodes are a set of references on topics (sub-topics / categories of analysis units) related to research problems [14].

IV. RESULT

LRD Member SuarAutisme is a virtual community that was established offline in October 2001 by distributing free bulletins. On October 23, 2010, this community arrived on Facebook in the form of a closed-group. LRD Member SuarAutisme played a major role in the exchange of information for its members in disseminating information about ASD. Most parents seek information through this virtual community to reduce uncertainty about diagnosis and intervention for their children.

To reduce this uncertainty, parents exchange information by 1) asking the admin about an issue 2) asking other members about an issue 3) exchanging experiences between members 4) seeking reinforcement and emotional support 5) giving reinforcement and emotional support from member to other member 6) giving information and reinforcement from admin to member. When a member asks, other members and the admin will respond. Admins also often upload information that members will respond to. This information exchange occurs in almost all activities in the virtual community. The process of asking about an issue done by a community member both to the admin and other members is basically a form of information support seeking. Information becomes important because the presence of information can reduce the level of uncertainty over a health problem, in this case is about autism. When a child got a diagnosis of autism from doctors, psychiatrists, or psychologists, parents are in a state of uncertainty. Parents mostly worried about child's condition, especially in decided the best interventions for their child (such as therapy and treatment), and even confused with the child's future. They need as much information as possible to reduce this uncertainty. So, joining a virtual community is one way for parents to obtain information that can be accounted for, even though they had consulted with a doctor. Strengthening of fellow community members is important and is considered important for parents since other members also had the same problems about handling ASD children.

When members met difficulties and obstacles in dealing with various problems raising ASD children, emotional support was needed. To get this emotional support, the communication behavior that occurs was a member confide about her problems of taking care ASD children. This confession was then responded by other members who usually told their experiences when handling their children. It was a kind of sharing experience about handling or giving intervention of ASD children. Identification of problem similarities with sharing experiences from other members will provide reinforcement to members who confide that everything will be passed as well as had happened to members who share their experiences. Sometimes there were also members who didn't share their experiences (because they might not have the same problem) but still provided emotional support by expressing empathy.

Table 1. Information exchange in virtual community to reduce uncertainty of parents with ASD children

Examples of posting

Asking the admin about an issue	<i>Sorry Ma'am. I want to ask, why my son still didn't want to socialize with his friend. When first time I invited him to enroll in this school, he was so happy. He saw almost all classes, but after the learning process starts, my son did not want to go to the classroom. He preferred to study and play alone. If someone directed him to enter his class, surely he rebelled and cried. What happened to my son? Give me suggestion, please. Thank you.</i>
Asking other members about an issue	<i>Morning everyone, I want to confide again. I have been applying the CFGFSF (Casein Free Gluten Free Sugar Free) diet for two weeks to my child, but the behavior has not changed. Is it true that the process of changing behavior not that fast? Or the diet that I applied was wrong? I have followed AIDS; Ayam, Ikan, Daging, Sayur(chicken, fish, meat, vegetables), no milk, no sugar. Already doing ABA therapy at home, but he still tantrum and crying..</i>
Exchanging experiences between members	<i>My child was just starting the CFGFSF diet too. It had not shown significant changes yet, but the hyperactivity is somewhat reduced and there has been eye contact even though briefly. Tantrums becomes rarely.</i>
Seeking reinforcement and emotional support	<i>I was confused about how to deal with my child with speech delay. He has been stayed with my mother for quite a long time so my mother had spoiled him. Now he stays with me and my husband, far away from my mother. My child becomes lazy to learn. Not obedient. He loves chocolate snacks because it was given by my mom every day. I'm so hopeless with this situation..</i>
Giving reinforcement and emotional support from member to other member	<i>Be patient mom, it would be hard at the beginning. My child is also doing therapy, and in the seventh month, her temper tantrum and hyperactivity was reduced, and even he started his verbal. Just keep going on your diet and therapy. Be sure that the effort wouldn't betray the result.</i>
Giving information and reinforcement from admin to member	<i>Finished the diet ma'am ... maybe some are still tucked away. Vary the paperwork at home. Play activities while studying should be improved to make your child focus in learning.</i>

In figure 1 there are information exchanges between members and admin in order to reduce uncertainty about handling ASD children. Communication through virtual communities brings its member to ask and receive information in handling ASD children by giving intervention such as diet and therapy. Uncertainty can be reduced by obtaining information and emotional support from both community members and admins.

Informational and emotional acceptance from member who asking information or support becomes a proof that uncertainty could be reduced by this communication behavior. It can be seen in table 2.

Table 2. Informational and emotional acceptance

	Examples of posting
Informational acceptance	Thanks for sharing mom. I wish my son could be like

your daughter or son.

Thanks a lot, dear. Don't be bored for sharing.

Emotional acceptance

Yes mom, thanks for your support.

V. CONCLUSION

Virtual community becomes one tool for parents of ASD children to obtain information and emotional support. The condition of uncertainty when parents receive a diagnosis of autism in their children causes parents to find as much information as possible to reduce the uncertainty through the process of exchanging information in virtual community. To reduce uncertainty, parents of ASD children exchange information by 1) asking the admin about an issue 2) asking other members about an issue 3) exchanging experiences between members and admin 4) seeking reinforcement and emotional support 5) giving reinforcement and emotional support from member to other member 6) giving information and reinforcement from admin to member.

This drives an implication for medical workers who interact with parents of ASD children to recommend them to join in a community, not only face-to-face (offline) community, but also online community.

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