

INTERPERSONAL COMMUNICATION PATTERNS IN VIRTUAL COMMUNITIES OF PARENTS WHO HAVE CHILDREN WITH AUTISM

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ABSTRACT: Autism is one of the social problems that occur in various worlds as well as in Indonesia. This study explores interpersonal communication patterns that occur in virtual communities of parents who have children with autism. Data collection method with virtual ethnography. Researchers observed the WhatsApp Group (WAG) "Anak Istimewa" which is a community of parents who have children with autism. In addition to observing WAG researchers also conducted interviews with an expert and ten parents of WAG members. The paradigm of this research is constructivism. The results showed that interpersonal communication patterns in reducing uncertainty began with WAG members actively telling the problem by opening up. Then, there is an interaction between members who are experiencing uncertainty and experts who offer solutions. Interactions between members and experts provide solutions and encourage WAG members to implement diets to achieve recovery in children with autism.

Keywords: Interpersonal Communication, Virtual community, Autism

I. INTRODUCTION

The prevalence of Autism Syndrome Disorder (ASD) or so-called autism continues to increase in the world. Recorded one in 59 children identified with autism disorder and reported to occur in all racial, ethnic, and socioeconomic groups [1]. There is no definitive data on the number of autism in Indonesia, but based on data from the Central Bureau of Statistics (BPS) on the population of Indonesia and the population growth rate of 1.14 percent per year, it is predicted that people with autism in Indonesia reach 2.4 million people and there is an increase of 500 people per year [2].

The social problem arising from the prevalence of autism is the high level of anxiety (stress) of parents who have children with autism. Stress is caused by challenging children's behavior. Little knowledge of autism and an environment that doesn't understand autism keeps parents from getting support. Stigmatization of society in children and parents makes parents feel ashamed, isolated, and avoid face-to-face. Professionals provide ever-changing diagnoses adds to the stress and confusion of how to treat and care for children with autism. The complexity of parental problems makes them experience uncertainty, thus seeking information about health through internet devices [3]. Some experts explain that uncertainty will shape interactions especially in terms of health [4]. New media has the opportunity to create groups or communities as a forum for discussion in other health and social fields [5].

The rapid development of technology and the emergence of various social media as a means of communicating and interacting for the community bring various implications, one of which is the emergence of various virtual communities that have various purposes. The presence of a virtual community on Facebook in Malaysia can answer the needs of parents of children with autism in seeking information and getting support [6]. The autism community on Twitter and Blogs has a significant role to play in providing social support for parents especially to overcome the challenges of caring for ASD children and is considered effective in reducing psychological stress on parents and caregivers of ASD children as well as improving the quality of life of someone diagnosed with ASD [7]. Parents can use social media to share with other parents and all members feel part of the community on matters relating to child behavioral care issues [8], [9].

The efforts made by members in the members in a virtual community to seek information and respond to members in discussions facilitated by the media called interactions[10]Although only in cyberspace, the interaction and intensity of two-way communication built can be a reinforcement for parents[11]and sources of information when in need of specific information related to children's health[12]. Facebook is a virtual community that parents can use to get support [11], [13]. The use of social media as an effort to find forms of social support as additional support they do not get from professional care that can help cope with the pressures of caring for their children gained from the experiences of others [14]. New media has the opportunity to create groups or communities as a forum for discussion in other health and social fields[5].

WhatsApp group (WAG) "Anak Istimewa" is a virtual community formed because of the same constraints, challenges, and needs. To make the community a forum for discussion, wag founders make rules that must be met by all members. In addition to parents who have autism children, this community also consists of professionals, experts, and practitioners who are interested in autism. Messages influence attitudes only when people understand, process, and remember those messages and feel motivated to apply them in their daily lives. To make the message effective, communication needs to respond to social cues and specific needs. The principles of interpersonal communication that apply are different and build the motivational scale of interpersonal communication to explain the dynamics and motivate a person to communicate interpersonally[5].Related to this, the purpose of this study is to analyze interpersonal communication patterns in the virtual community of parents who have children with autism.

II. RESEARCH METHODS

Research is qualitative research by using the virtual ethnographic method on Whatsapp Group (WAG) "Anak Istimewa" which is a virtual community of parents who have children with autism. Virtual ethnographic studies consist of several steps, among others: observing and exploring objects; select an object and seek approval; enter the community and make observations; selecting an analysis category; continuing observations; analyze data against the background of theory, and create narratives. Based on the guidelines, researchers chose WhatsApp Group (WAG) "Anak Istimewa" because it is relevant, active, windy, extremist, heterogeneous, and rich data [15]. WAG members numbered 235 people (data until June 30, 2020), coming from all over Indonesia and even abroad. The community consists of mothers or fathers who have autistic children aged 2 to 18 years. The age of the mother ranges from 25 to 48 years, while the age of the father ranges from 29 to 42 years. High school education level up to S2.

After establishing WAG "Anak Istimewa" as an analysis unit, the researcher requested approval from the admin and founder of Wag Anak Istimewa in January 2020. After obtaining approval, researchers began observing the WAG by analyzing text taken in March and June 2020. Researchers also interviewed 8 mothers and 2 parents of children with autism. Wag members are dominated by women (mothers). The number of women is 81 percent of the total members, while the number of men (fathers) is only 19 percent. Men who are wag members are only a complement to strengthen interventions made in children. In-depth interviews are used to collect data on interpersonal communication that occurs with THE WAG and answer questions related to research objectives.

By the characteristics of qualitative research in general, data analysis at the time of the study opens the opportunity to give birth to follow-up questions, and spontaneous observation without having to be tied to space and time at the time of research. Furthermore, the collected data is analyzed using analysis techniques [16]. Data processing using the help of Nvivo 12 plus for coding and categorization of observation data and interview transcripts.

III. THEORETICAL FRAMEWORKS

Uncertainty Reduction Theory

Uncertainty Reduction Theory is the basis of interpersonal communication. The beginning of the theory was created to deal with uncertainty in the communication process when two strangers interact. Individuals will seek information to reduce uncertainty when continuing interactions in interpersonal communication[17]. One of the behaviors of information retrieval is an active strategy that they will make an open effort to obtain information, although sometimes not to the direct target[17].

Trust factors in people who interact, their ability, and privacy concern are predicted to reduce uncertainty. In the end, it has implications on the amount they express to individuals, and ha is widely found online communication[18]. Uncertainty occurs when dealing with complex, probabilistic problems, information available is fickle or people have no restraint on a thing.

Uncertainty Reduction Theory (URT) has been applied to various communication contexts both inside and outside the original scope of the theory[17]. URT has been used and combined in a variety of issues such as health communication, social organization, marketing, and clinical supervision. In the field of interpersonal

communication, the most prominent URT applications have been in the early arenas of interaction, social exchange processes, individual differences in uncertainty, established relationships, computer-mediated communication, interpersonal communication within the organization, and inter-cultural communication. In health communication, the situation of a person who is in uncertainty encourages to conduct information search and form interactions between patients and experts. The search for information plays an important role when patients are faced with uncertainties including diagnosis, intervention options, and social roles[4]

IV. RESULTS AND DISCUSSIONS

The focus of the study was to analyze interpersonal communication patterns that occur in the virtual community of parents who have children with autism. Based on the analysis of the messages shared and comments on the message, it can be explained that the exchange of information occurs throughout the interaction in the virtual community. Interactions on WAG involve message-based actions and reactions (chats). The exchange of information occurs throughout the interaction in the virtual community describing that three actors play a role in the virtual community or WhatsApp Group (WAG) "Anak Istimewa" namely members, admins, and experts. These three actors have different roles and functions in the virtual community. Members and admins have almost the same role because admins are parents who have autistic children, so their role is to seek information related to autistic child care. Admin has a role that is as a selection of the entry of new members and removes members who are judged to have violated WAG rules, especially if previously had received a warning. Also, admins sometimes have a role as intermediaries if there is a case of debate between members. This virtual community attracts because of a high level of activity in the community (averaging several hundred messages per file a week), and strong evidence of social support and trust in the virtual community. Members of the community ask and answer questions related to childhood autism and provide support and encouragement to each other and answer uncertainty.

The rules set by admins become social control in the WAG community, so each member is free to search for information, ask questions, express ideas, thoughts, ideas, exchange experiences, and share the content they share with due regard to applicable norms. This is done so that the virtual community becomes a place to share and discuss conducive and comfortable. Besides, established norms can avoid conflicts within groups. The rules of the group build the understanding of each member who has a different background to take advantage of freedom with a sense of responsibility. With the rules set by WAG, members managed to foster positive values as well as useful information for themselves and the community. Interactions that occur can be grouped in two forms, namely: interactions between members and interactions between members and experts. The interaction was facilitated by four admins by applying social rules and shared behavior in the WAG.

WAG members interact to find information and make the community a means to solve problems related to autistic children's disorders. In the virtual community, group members are free to communicate, exchange information, and share experiences. Interactions that occur in the community boil down to information that is divided into two things, including (1) members sharing problems and (2) experts sharing solutions that will be described in the following discussions:

Members sharing problems

Members actively engage in interpersonal strategies by sharing problems. When first interacting in the community, there is no specific search by members about any form of intervention. They only complain about sharing problems related to children's behavior, stigmatization, and other issues related to autism. Members disclose personal identities such as the age of the child, diagnosis, behavior (hyperactivity, tantrums, no eye contact, not yet able to speak, which is the hallmark of the child's autism), and experiences when caring for a child with autism. The behavior of the child they share and express hope of getting a solution for the healer. Parents with autistic children use WAG to seek information by asking questions, sharing experiences, and seeking relevant forms of social media support[14]. Like a mother's story, when she finds out her son has autism, she experiences anxiety and uncertainty. He felt the world seemed shattered and asked what mistakes I had made in having a child with autism. Another mother expressed dissatisfaction with the offline support, as she continued to search for information about her son's recovery online. He stated "that doctors are often fickle in providing diagnoses.

In general, members expect their children to develop and grow normally like other children, especially in terms of social communication. One of the difficulties experienced by children with autism is that it makes it difficult to socialize. Parents share their problems openly hoping for a solution to their recovery.



The Expertsharing solutions

The Expert conducts Interpersonal communication to provide messages in the form of interventions that can be a solution for parents in the treatment and care of autistic children. A socialized solution is a diet of broths, vegetables, and meats (kalsada) that are high in nutrients. Kalsada diet is a traditional diet using available ingredients, affordable, and easy to get. Kalsada diet adopted from GAPS diet (Gut and Psychology

Syndrom) is a health protocol created by nutritionist and neurology Dr. Natasha Campbell Mcbride from Russia[19]. She believes that there is an absolute relationship between physical and mental health, food and drinks consumed, and the condition of the digestive system. People who have GAPS syndrome are malnourished. The recommended diet is nutrient-dense as the foundation for the development of children with autism, to accelerate the recovery or eliminate existing disorders (symptoms). As is known the human body will be able to absorb nutrients well if the digestive system has undergone normal growth so that it can absorb food nutrients that enter the body.

The Experts send messages many times into the group that children with autism have indigestion, leaky intestines so that nutrients cannot be absorbed into the brain, with various other explanations accompanied by words just ideas, references, and suggestions.

Here's one of the expert messages shared in the community.

13/03/2020, 14:54-Ai Grace: Growth and development have a map, as is the child with autism. The foundation of the process of building capabilities to reach the most complex stages is nutrition (see diagram  [..]). Diagnosis of any negative impact is constrained growth process. For example, if the sensory is immature, then the input reception process is interrupted. When input entry is disrupted, how will the brain manage information appropriately and then be able to respond appropriately? There are obstacles such as lack of eye contact, not turning when called, difficulty receiving directions, not fluent speech, weak muscles to move, etc. When parents should choose the best nutrition to improve developmental disorders / mental (diagnosis), what should be chosen so as not to waste time, money & energy, and safe? My choice is natural ingredients containing minerals, vitamins, zat2 that the body needs, especially the brain. Why KALSADA (vegetable-meat broth? Because the broth contains FAT that in addition to the brain needs but also able to restore the condition of the intestines leaking / indigestion. Fat is also able to bind toxins & help remove them from the body. Note: nutrients in the body ananda with a diagnosis usually can not reach to the brain due to leaky intestinal conditions, the abundance of fungi, harmful bacteria & patogen2 other in the intestines are excessive, mainly because of consuming intake containing sugar continuously. VEGETABLES: contains carbohydrates in addition to other beneficial vitamins & minerals. MEAT: contains proteins that are needed by the body, especially the brain. In this group, it is very noticeable significant changes in the ananda with pure KALSADA (without rice plus without other therapies). I've dealt with over 1000 children, only before [..] Just an idea, suggestions hopefully help 

According to interviews with an expert, the idea given is an idea that has done a long process through the learning process, the results of discussions with scientists from abroad and has been applied, practiced then through the evaluation process. Interventions offered by experts are porous on the disorder (symptom), so it can be applied to all children with autism. This is as the GC (expert/neurologist) states that:

The idea of clinicians and practitioners is to go through a long process, learning, discussions with many foreign experts, applied, practiced, evaluated, and then applied. This intervention does not take into account age, gender, culture, locality, or geography but we consider the condition or symptom because what is to be eliminated is the symptom. So the shaft has to be a symptom.

(Interview with Expert, GC, June 04, 2020)

WAG Interpersonal Communication Patterns

Based on the above discussion, it can be identified in WAG interpersonal communication patterns begin with parental complaints and their child's behavior. Then, experts provide information or ideas in the form of solutions. Information submitted by experts, relevant to the problems of parents, so that members who want to know the information most actively ask to satisfy curiosity about socialized interventions, to solve the problem at hand. Also, other members make comments such as empathy, sympathy, encouragement, and prayer. Content in the form of solutions from experts accompanied by the willingness of experts to supervise the insertion of the diet kalsada. and testimony of the experience of parents who have applied the diet by telling the development of the child motivates parents to apply the diet.

Interaction between members and experts using active strategy so that there is openness from members and solutions from experts. The openness of members on the problems faced also elicits empathy, sympathy, and support from other members. In interpersonal communication, experts can build trust so that they are considered leaders of opinion. The leader of the opinion on online social support is someone who has a higher level of knowledge of a disease or someone optimistic and successfully dealing with the disease[20]. Expert conduct persuasion communication to encourage parents to implement the early intervention with diet and are willing to supervise diet for group members. Virtual community interaction encourages members to adopt a kalsada diet. Furthermore, members who apply the diet are required to fill out a journal and report the child's development to the group. Parents who apply the kalsada diet report the obstacles faced in the diet such as children who choose eater, difficulty stopping the consumption of milk in children, children who do not want to

eat, and so on. While another positive impact that looks negative is the die-off phase. In this phase, the child looks limp, not passionate, feverish, sometimes vomiting. Expert provides motivation and encouragement so that parents do not give up because of the die-off phase, because in this phase, the body is removing toxins from digestion. Digestion is the second brain in the human body, then if the child's troubled digestive condition becomes uncomfortable. If the intestines leak, food nutrients are not channeled to the brain, so the child's development is disrupted.

In addition to the problems and constraints of the kalsada diet, members also share significant development of children in the form of words, photos, or videos. The behavior of the child turns calm (not tantrum), focuses, begins to be able to issue words. The child can receive therapy well. Openness about a child's development elicits praise and appreciation such as the words "great", "amazing", or symbols in the form of "virtual affection" on WhatsApp social media. Praise and appreciation motivate members to consistently implement a diet in achieving child recovery. While members who have not to diet are motivated to apply the diet kalsada. Praise and appreciation both in the form of words and virtual affection are important to support parents who are on a diet. This adds to the motivation of members who apply the diet. The development of the child due to the application of the diet motivates other members to apply the diet. When a member has applied a diet and feels its benefits, it becomes a new source of information that provides new information to the new member who will apply the diet. They repost expert explanations and recount experiences during the diet that result in significant development. Interactions between members and members expertly provide solutions and encourage WAG members to implement a diet to achieve recovery in children with autism. New members who will apply the diet, in addition to getting information from experts, also get information from other members who have already applied the diet. They re-post expert explanations about kalsada. As a mother says:

Support from experts and other members in implementing an intervention is very important, especially when I have just been on a diet for my child. I also provide information about kalsada by reposting the expert explanation if anyone asks. I always give asterisks for things I think are important and I will share them with other members.

(Interview with members, HL, June 18, 2020)

V. CONCLUSION AND RECOMMENDATION

Interpersonal communication patterns in reducing uncertainty begin with WAG members actively telling the problem by opening up. Then experts conduct active communication with messages in the form of solutions to the problem of members namely the diet of broth, vegetables, and meat (kalsada). Expert explain all things related to the application of diet, benefits, dietary protocols, the experience of dealing with thousands of children with autism, and addressing problems arising from the diet. After that happens interactions between members who are experiencing uncertainty and expert who offer solutions. Active and reciprocal communication makes members more open and trusts in experts, so experts can encourage members to apply diet. The development of the child due to the application of the diet motivates other members to apply the diet. When a member has applied a diet and feels its benefits, it becomes a new source of information that provides new information to the new member who will apply the diet. They repost expert explanations and recount experiences during the diet that result in significant development. Interactions between members and members expertly provide solutions and encourage WAG members to implement a diet to achieve recovery in children with autism.

The results of the study may be an input for medical personnel dealing with parents of ASD children to recommend they join a community to improve knowledge about autism child care. The amount of information from parents who have autistic children has great potential to use the social media community as a source of data mining in determining policies, developing early treatment or intervention on autism and other health problems, and in collaboration with private parties and professionals/experts.

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