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Information Sharing Behavior among Parents of Children With *Autism Spectrum Disorder* (ASD)

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Abstract

The information needs of children with Autism Spectrum Disorder (ASD) can be fulfilled optimally when their family give great attention in educating and caring for them. Families especially parents, is the first and important person that encourage the growth and development of their children whether physical, psychological, mentally, communication, personality and emotional. This study aim to describe about information sharing behavior among parents of children with ASD and determine the factors that encourage and inhibit the occurrence of information sharing behavior among ASD parents. This study used a qualitative approach, choosing informant by snowball technique to determine key informants from Autism Awareness Advocacy (ASA) community members which exist in Surabaya Indonesia. By interviewing seven informant, the result show that information sharing behavior among parents of children with ASD has two typology, namely passive behavior and active behavior. Information sharing behavior activity among ASD children could be examine by using Homan's Social Exchange Theory (SET), by realized through three SET propositions which are successful, value and approval-aggression, and two new proposition which found in this study, technology and productivity. On the other hand, there are external factors that affect information sharing behavior success such as reward, trusts, and family support, and internal factor such as anger, satisfaction, and self efficacy. This research provide benefits for parents of children with ASD especially members of the ASA community by sharing information and to increase the independence of their ASD children. Besides that, parents could expand the possibilities for the realization of the factors that suporting the sharing information activity, so the success of their children to interact in society would increasingly widespread.

Keywords: Children with Autism Spectrum Disorder (ASD), parent of ASD children, information sharing behavior, social exchange, active behavior, passive behavior, external factors, internal factors

Introduction

Indonesian government has provided guarantees and legal protection of the rights possessed by children with ASD, which intended that they can grow and develop optimally in accordance with the status and dignity as human beings. Hasdianah (2013) explains that children with ASD is a child who has a very complex disorder primarily on the development neurobiologist, where the disorder is seen in social interaction, the way they communicate, use of language, also resulted impact on the emotional, sensory perception and body movement. ASD also identified as developmental disorder of neurobiology at someone, in general, these disorders result in persons with ASD that will have difficulty in communication, social interaction and adapted to the environment (Association for Library Service to Children, 2015).

Peeters (2012) explains that ASD is a developmental disorder on understanding or pervasive disorder and not a form of mental illness. This means that children with ASD is different with children who have special needs in mental disorder, but children with ASD at the same time may also experience mental disorder. Along with that, Mulyadi and Sutadi (2016) which concerned on education for children with ASD, have explain that essentially the disruption of neurobiology that occur in children with ASD can cause problems with their capability in communicating and adapting to the surrounding environment. ASD children's needs can be met optimally when their parents play more active role in giving attention to educating and caring for ASD children. This opinion supported by Hadith (2006) which says that parents are the decisive factor in the development of their children. Families, especially parents, is the first environment that characterizes the growth and development of their children, whether physical, psychological, mental, communication, personality and emotional.

Further more, Hasdianah (2013) mentions the ratio number of children with ASD in the United States is 1:150, while in the UK 1:100, unfortunately until now, Indonesia have no accurate data about the number of children with ASD. In 2013 the ministry of health estimates the number of autistic children in Indonesia around 112 thousand age range 5-19 years, but the number still uncertain. A sure things precisely is in almost all Indonesia city we can found ASD children communities which their mission to protect and advocate ASD children, their family and society. One of those communities which run that mission (care for the rights of ASD children's) is community of Autism Awareness Advocacy (ASA) in Surabaya. This community pioneered by Mia Okky Oktavian, who have a great concern in the development of ASD children. The members of this community is very diverse, made up of various person such as psychologists, therapists, and parents who have children with ASD. This community has a lot activities pursued by children and parents of children with ASD, they tried to equipped parents with information weather by educating or taking care, and improve the growth and development of children with ASD. The therapists and parents mutually transfer information and a variety of experiences like how to care, improve the growth and development of children with ASD, and develop their physical, motor, cognitive, and psychosocial ability. Puspita (2001) also said that a crucial role of parents of ASD children is helping them to achieve optimal growth and development.

Based on this, children with ASD require more attention from their family especially their parent (as the central figures) to achieve ASD children's success in their live. Parent's would help their children to grow up like most children in the world, they always continue to find right information and expert to handle their children. This research try to describe activities of sharing information behavior among parents of children with ASD, and also analyzes the factors which become supporting and inhibiting the occurrence of information sharing behavior.

Literature Review

Information Sharing Behavior

As a part of knowledge management concept, information sharing behavior is an act of sharing information by individuals and groups with the purpose, manner, and certain media. This behavior could be examined by using Homans's Social Exchange Theory (SET) which can help to uncover the background of individual or group perform an act of sharing information and also as a guide in revealing the background why someone doing that behavior. Social Exchange Theory (SET) propose appreciation in the exchange between people, and prioritize in social relationships. SET is one of the paradigms used to understand the behavior of information sharing because it regarded as a social realm. Among several theories that used to discuss and explain about information sharing behavior, SET based on the premise that individuals who conduct activities to share information with others will hope to achieve same thing or more (information) from the person who shared it.

Homans (in Ritzer, 2012) says there are several propositions when applying information sharing behavior in SET theory;

- a. **Success:** the more often certain actions is given award, the more likely that person to perform that action.
- b. **Stimulus:** is a set of stimulus behind one's actions have an award, if the same stimulus in the past with the present and or deliver success, then that person is more likely to implement the same action.
- c. **Value:** the results of one's actions for themselves, the more likely individuals to perform action, describes the value of the action taken. Obtaining positive results and penalties for negative results.
- d. **Saturation-Losses:** the more often a person receives a particular award, both in the past then diminishing to him the value of the award, he does not repeat his actions.
- e. **Aggression Agreement:** this proposition has two views in addressing the situation occurs, the first proposition A action when someone does not achieve the expected award, or receive punishment he expected, it can cause effects such as anger, aggressive behavior. The second proposition B, when the award received is greater than expected, or did not receive the expected punishment, than it becomes more value for him. The second proposition is that a person's attitude on the action he had received and made to be negative (proposition A) and positive (proposition B)
- f. **Rationality:** people will choose an action as motivated by alternative measures, when there are two or more actions, he will choose the action that has considered greater value.

In accordance with the Huang opinion (2018), SET explain the behavior of individuals in performing an activity including information sharing activities itself. As Suneson and Dan (2012) explains that the information sharing behavior will faced some obstacles, including the following;

- a. Individual: the lack of confidence (self-efficacy), personal communication, interaction, position, time and trusts
- b. Technology: the technology gap
- c. Organization: the lack of reward from the organization, the organization's environmental conditions and work culture that are not supportive.

Research Methods

This study used a qualitative approach that aims to understand the phenomenon, which experienced by the subject of the study such as behavior, perception, motivation, and action, more holistic and describe the form of words and language in a natural context

(Moeleong, 2007). This research conducted in Surabaya by choosing ASA community as the autism community which routinely carry on sharing information activity amongs the members. By using snowball technique, this research take a key informants from ASA community members as a preliminary to determine the next informant. The most active members from this community are mother of children with ASD, some of them are working outside their home but some are house wife. ASA Surabaya community is one of ASD community in Surabaya Indonesia, which concerns and protect the rights of persons with ASD, as well as to educate the public about ASD existence. This community has conduct meetings regularly, equipped parents with information how to take care of the growth and development of children with ASD, share information and various experiences between parents in how to taking care of ASD children, and also prepare them for being part of society and adjust to the surrounding environment.

Result and Discussion

Information Sharing Behavior among Parents of Children with ASD

This study was conducted by interviewing as many as 9 informant who is a member of the ASA community, and after data reduction there were only 7 informants who meet the requirements to this research. The first informant (OA.1) admitted that she needs quite a long time to accept her ASD children condition, after several years, she started to engage in sharing information with other family particularly who have an ASD children. Information sharing activities gave her a lot of usefull information and some benefits to support her children's growth and involved in various activities in society. Informant OA.1 strongly feel comfortable when doing information sharing, although she only had limited time (because she is working women) but she still could felt the benefits from that activities, and very enthusias when implement the information then improve her son condition. Second informant OA.2, also aware of her needs about the right information to support the development of her ASD children, that why she always spend her time participated in the sharing information activities arrange by ASA community. Not only doing share information, informant OA.2 try to make several campaigns, sharing experience in specific activities like in *Car Free Day programe* to rise society awareness of ASD in a wider scope.

Informant OA.3 got motivated to join sharing information activities because medical expert identified her daughter condition as children with ASD whose unable to communicate and speaking fluently. Her daughter was very passive, therefore she keep trying to implement a lot of information through a variety experiences, receive an advice from other parents, even no significant change from her ASD children condition. She's very eager to help her daughter to socialize and explore her own potential in society. Actually, she's ever had uncomfortable experience during the years of sharing information with another parents of children with ASD, then she decide to stop conducting face-to-face sharing activities and now prefer sharing information via social media like Whats Up.

The next informants is OA.4, as one of founder ASA community which had a lot of experience about caring for and raising children with ASD, because she not just have one children with this syndrome, but she had two children. As initiators of ASA community, she following vary programe like seminar, workshop, and training, and OA.4 also actively being a speaker on behalf of ASA community in many kind of activities than sharing all information that she had. She likes to share information by any media, like directly through face-to-face discussion or by using sosial media. Just like OA.4, fifth informant (OA.5) feel motivated to continue exploring ability that owned by her ASD children. She comes to join various sharing activities to get all information about ASD children like how to keep children

with ASD independent and explore the potentiality of her children. The fifth informants also very actively looking for news from mass media (radio, television, internet) which discusses about development of children with ASD. Actually, she felt more confidence if she knows that information that she would try to apply already implemented by other parents who have success in caring and educating their children with ASD. Unfortunately, during sharing information activities, OA.5 prefer to receive information from someone else (as listener) rather than being an informer who shared her own experience.

Different experience occur for informant OA.6, she feels comfortable sharing information about her children condition only with her close friends. She ever participated in ASA community, but after unpleasant events happend to her, now she have no longer interested in that community. Informant OA.7 very active asking about how to deal with development of children with ASD, lead them to success, develop accordingly to their age so they can participate in their community. She is very enthusiastic to share information with other parents of ASD children, because she know that information sharing activities can be one of the keys to success in caring and educating for independence of children with ASD. She also active in sharing information through social media such as mailing lists, whats up, and facebook. On her daily live, OA.7 always follow sharing information activities about the success and experience behind caring on ASD children in ASA community.

Based on data findings, there are two typology of information sharing behavior among parents of children with ASD, as shown below:

Table 1
Typology of Information Sharing Behavior among Parents of Children with ASD

No.	Proposition	Active Parents (OA.1), (OA.2), (OA.4), (OA.5), (OA.7)	Passive Parents (OA.3), (OA.6)
1.	Success	<ul style="list-style-type: none"> • High share activity • Implement new information for their children's daily life 	<ul style="list-style-type: none"> • Low share activity • Afraid to implement information, avoiding failure
2.	Value	Continued sharing with others	Keep information for themself (stop sharing)
3.	Approval-Aggression	always sharing in high intency	Doing nothing
4.	Technology	Actively used and exploited various social media (whats up, facebook)	Used media, but tend to be silent reader
5.	Productivity	<ul style="list-style-type: none"> • Writing an essay in some media • Active as a speaker in seminar, workshop • Critical in facing ASD conditions 	Choose as followers

Based on table 1, it can be seen that there are two typologies parents of children with ASD in information sharing activities, namely active and passive parent, we also can see that activities realized through three SET propositions which are successful, value and approval-aggression. By this research, we found new proposition which are technology and productivity, which intended to expand study about information sharing behavior especially when using SET theory. Information sharing behavior among parents of children with ASD have some differences and similarities, like interest in sharing, the media used, as well as factors that underlying parents of ASD in sharing information.

Active behavior shown by parent who has a high motivation doing information sharing, otherwise, passive parent is who has a low motivation in sharing information. Active behavior motivated success, value, approval-aggression, technology, and productivity proposition, while in passive behavior all that proposition are very limited. Uniquely, on active behavior sometimes they received denial of their children presence from society, but it keeps them motivated to show them that their ASD children are worth to be considered as part of useful young generation, so they will struggle to get recognition of their children's where abouts. Their actions motivated by supporting from their extended family, willingness and high morale within. As an active behavior, parents not ashamed or withdrawn their ASD children from the society, they must dispose of personal ego and put forward the condition and development of their children, as they realize parents is the first person responsible for the children development both psychologically and mentally. Parents should start to open up the social environment thinking, such as tracking the activities held by information sharing related community or with other parents who are active through social media. The more often the parents do sharing activities, the more benefits that can be taken, such as the emergence of their own creativity which is able to share about the development of children through certain media such as facebook, whats up or mailing list.

On the other hand for passive parents, information that they have or received from someone would not be share or just stay on their mind. For passive parents, information will quit on them even that is valuable information and the less it matters when they feel information is not worth, at the same time, they stay think and feel that the public response to ASD children is negative. According to Homans in Ritzer (2012), the more valuable acquisition of positive result, the greater a person want to repeat the act. Table 1 shows that in the proposition of approval-aggression, for active parents they keep doing sharing information even though they received rejection from family environment which should be the most supportive. They really want to share information intensively with other parents of ASD children, beside that, the more they aware the lack of attention from local government's to serve the rights of ASD children, than they even more active in sharing information to sounding their mission and vision, so that the presence of children with ASD in the world can be considered. Homans in Ritzer (2014) says that when a person's actions are not as expected, it will arouse anger and aggressive behavior. The parents will be very aggressive in this case the supporting of their attitude like making activities in the public space to increase society awareness on ASD, they hope it can change the public intention for more consider on ASD children.

In Table 1, we also can see that successful proposition make active parents to continue sharing information activities, they will be perpetually very intensive sharing information and will implement information they receives on daily live but passive parents only share information when there is a stimulus or only under certain conditions. Homans in Ritzer (2012) states that a person's actions are the result from award, when she received award (useful information) means more often then the individual is going to do the same action (sharing information). Studies which conducted by Paraskevaidis and Andriotis (2017) stated that the SET take into account the compensation, in accordance with interpretation in this study that describes the awards received by parents of ASD children to make them repeat the sharing action.

Waldkirch (2018) also states that it is very possible that the SET theory can achieve a successful process in describing information sharing activities, because awards (useful information) that someone have received from someone else would make her (parents) more and more desire to repeat the same action (sharing information). (Andriotis & Vaughan, Coulson 2003; .et al, 2014; Erotokritakis & Andriotis, 2006; Monterrubio & Andriotis 2014; Sharpley, 2014). Li Jinyam (2015) also said that information sharing behavior in the scope of

SET significantly contribute in the long term to achieve success in the information sharing activities. Value proposition has showed that for active parent, they would never stop doing sharing useful and important information because they know that information have high value. Positive response from the public also supporting parents feel meaningful and necessary, because they know that there is a positive response received by the community from information they share. Parents have no doubt that information is much more valuable when it shared with other parents of children with ASD. This means that the more valuable some information for them and make them satisfaction, the more they would repeat the action. On the other hand, denial of ASD children presence from social environment will make parents do not want to commit an act of sharing information (passive), it is because they feel embarrassed by their children condition, tend to hide their children from social environment, in addition, they consider that this condition is a providence from God that should they receive with graceful.

A new proposition that supporting information sharing behavior is technology, where parent who very active in utilize technology (social media) and use it as a tools to share information, like mobile phone, whats up, facebook and mailing list. Inversely with passive partents, they tend to not use technology as a medium in the activity of sharing information, and tend to keep information for themselves (silent reader). The existence of technology motivate parent to share about their children's growth. Yuliar (2009) says that there are two ways of technology determination in society, the first is development of technology determine society, where efficiency the use of technology makes people would use technology, while another is society determine technology, where the will and decision of communities determine the effects that arise from technology.

It can be assume that the technology has been determine parents of children with ASD in doing information sharing activity, they can not ignore technology because for them, technology were an effective medium to support that activities and perceived benefits which allows them repeat that activity again. This behavior appears in active parents whose doing information sharing activities as a highest levels of their needs in live, they become productive person to motivated others by actualizing their self as a speaker, writers, and actively sharing documentations associated with their children activities.

Influence Factors in Information Sharing Behavior among Parent with ASD Children

The emerge of five propositions are influence by internal and external factors that cause the information sharing behavior among parents of children with ASD emerge. Internal factors are things that come from individual (inner parent's of ASD children), while the external factor comes from outside the individual. The factors are as follows;

Tabel 2
Influence Factors in Information Sharing Behavior

No.	External	Internal
1.	Reward	Anger
2.	Trust	Satisfaction
3.	Family support	Seft efficacy

Internal factors either support or inhibit such anger, satisfaction, and selt efficacy, while external factors such reward, trusts, and family support. Parents anger can be useful to conduct the goals of vision and mission among parents and share it to the government to serve and facilitate the needs of ASD children in many aspect, such as education, transportation and public facilities. Second aspect from internal factor is satisfaction, parents feel satisfaction about the results of sharing activities, they assume that as many as parents

are informed about the material which had shared, the more they will get satisfaction and tend to repeat the information sharing activities. The third is a sense of trust on self or self efficacy, feeling confident that the sharing of information provides usefulness for other parents of ASD children.

Reward is an external factor in sharing information, frequently sharing activities either through print or online, increasingly encourage parents to get compliments and invitations to be guest speakers in a seminar or workshop, and they feel confident that sharing information provides usefulness for other parents of ASD children. Family support is another factor that motivated parents to perform information sharing activities, both material and imaterial greatly help parents to have a strong motivation in keep sharing information with other parents. If they not receive convenient reward, they still motivated to seek information because moral support from the peer group is very motivate parents to remain conduct information sharing despite in low intensity.

Conclusion

Information Sharing Behavior among parents of children with ASD has two typologi, namely passive and active behavior. Passive behavior occurs when the information sharing activities take place in low intensity. They receive information from face to face interaction or from some media, but unfortunately they not share the information (silent reader) to another parent or just implement the information only for their children. The information that parents share usually about the development of the child, how they can live independently, how they undergo daily live activities, and others.

The second type is an active parent who have a high intensity of information sharing activities, they very active in sharing information through various media and programe. They used social media such as whats up and facebook, they always share information about all their children activities, some tips when their children in school, in public transportation, how to support their growth, and many things. Parents in this category are productively to produce information to be more valuable and useful for parents and then shared it through various social media. Active behavior usually have their own program or events which conduct regularly to share information with other parents who have children with ASD, and also often be a speaker in seminar or get invitations from various related organization to give motivation on how to take care children with ASD.

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