

# **Communication Pattern of Dietary Intervention for Autism Spectrum Disorder Children on Facebook**

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## **Abstract**

*Autism Spectrum Disorder (ASD) children need appropriate treatment and intervention as early as possible after the diagnosis was made. Besides therapy, diet is one of the interventions that could be carried out by parents, although the positive effects of diet are still debatable among experts. This study aimed to understand the pattern of seeking information related to dietary interventions for ASD children in a virtual community of parent support group in Indonesia. The data was obtained from a virtual community on Facebook, named LRD Member Suar Autisme. This research was qualitative with virtual ethnographic method. The data collection technique was carried out through participant observation on the LRD Member Suar Autisme Facebook account, by examining 178 uploads, 3,569 comments and interview with community members. The results showed that the pattern of seeking information about dietary interventions by community members began with questions or seeking information regarding certain matters. In addition, it can also be identified patterns of presenting information about dietary intervention by admins. Our study showed that dietary intervention was one of the ways suggested by the community to reduce the improper behaviour of ASD children, especially based on the experiences of admins and members in the virtual community.*

**Keywords:** *autism; children; dietary intervention; Facebook; virtual community*

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# **Pola Komunikasi Intervensi Diet pada Anak Gangguan Spektrum Autisme pada Facebook**

## **Abstrak**

anak dengan Autism Spectrum Disorder (ASD) membutuhkan penanganan dan intervensi yang tepat sedini mungkin setelah didiagnosis. Selain terapi, diet merupakan salah satu intervensi yang dapat dilakukan oleh orang tua, meskipun efek positif dari diet masih diperdebatkan oleh para ahli. Penelitian ini bertujuan untuk mengetahui pola pencarian informasi terkait intervensi pola makan anak ASD dalam komunitas virtual parent support group di Indonesia. Data diperoleh dari komunitas virtual di Facebook LRD Member Suar Autisme. Penelitian ini bersifat kualitatif dengan metode etnografi virtual. Teknik pengumpulan data dilakukan melalui observasi partisipan pada akun LRD Member Suar Autisme, dengan menelaah 178 unggahan, 3.569 komentar dan wawancara dengan anggota komunitas. Hasil penelitian menunjukkan bahwa pola pencarian informasi tentang intervensi diet oleh anggota masyarakat diawali dengan pertanyaan atau pencarian informasi mengenai hal-hal tertentu. Selain itu, identifikasi pola penyajian informasi tentang intervensi diet oleh admin. Penelitian menunjukkan bahwa intervensi diet adalah salah satu cara yang disarankan

oleh komunitas untuk mengurangi perilaku anak ASD, terutama berdasarkan pengalaman admin dan anggota di komunitas virtual.

**Kata kunci:** *autisme; anak-anak; intervensi diet; Facebook; Komunitas virtual*

## INTRODUCTION

Autism Spectrum Disorder (ASD) is a condition of neurodevelopmental disorders of the brain that causes sufferers to experience difficulties in communicating and socializing. WHO states, ASD refers to a variety of conditions characterized by some degree of impairment in social behavior, communication and language, limited interests and activities that are unique to each individual and carried out repeatedly. ASD begins in childhood and tends to persist into adolescence and adulthood. In most cases, the condition is apparent during the first 5 years of life (WHO, n.d.).

People with ASD need treatment and intervention to minimize the symptoms that often accompany such as tantrums, mood swings or rapid changes in mood as well as stimming or doing activities repeatedly such as flapping hands, snapping fingers, jumping and so on. Implementation of interventions as early as possible for ASD sufferers is important so that ASD children can focus and concentrate better so that they are able to receive good learning. In addition to various therapies, such as speech therapy, sensory integration therapy and occupational therapy, ASD sufferers also need to adjust their diet or certain food diets.

Dietary intervention is considered important for ASD children because many parents had reported significant

development of their children who have been on the CFGFSF (Casein Free, Gluten Free, Sugar Free) diet. This significant development was indicated by reduced tantrums, increased focus, children who were initially non-verbal (not yet able to speak) became verbal, eye contact began to increase and children were easier to accept the learning material provided. One study stated that ASD children became more severe when their diet was leaked (Lucarelli et al., 1995).

Subsequent research stated that based on reports of parents who adhered to a strict gluten and casein-free diet in ASD children reported improvements in ASD behavior, physiological symptoms and social behavior (Pennesi & Klein, 2012). In line with this, there are studies that state that individuals with ASD who follow a gluten- and casein-free diet can reduce existing ASD symptoms (Cekici & Sanlier, 2017). Meanwhile, in Indonesia, research (Mukhfi et al., 2014) reported that ASD children in Depok City who had stable emotions were more likely to be on a diet (70.6%) than children who did not diet (16%). The study also explained that there was a relationship between dietary regulation practices and the emotional behavior of ASD children aged 3-7 years in Depok City.

In order to get information about dietary interventions and social support for ASD children, parents in Indonesia use

the internet by joining virtual communities on one of the social media platforms, Facebook (Purnamasari et al., 2019). This is also done by people with autism in China, who use virtual communities to seek information about dietary interventions. Autism intervention through diet has become popular in the virtual community since 2018 (Ni et al., 2022). Another study on virtual communities using Facebook related to ASD was also conducted in Malaysia (Mohd Roffeei et al., 2015), but in the context of parents receiving social support, not for dietary intervention.

In the context of health communication, virtual communities are a place for members to share information and provide social support regarding certain diseases or health conditions that they are facing. According to Schiavo, a virtual community with the topics discussed related to health problems will play a role in increasing awareness of health problems and community development issues. New media opportunities to create groups and communities that have something in common on health topics or social topics have influenced not only information seeking behavior, but also treatment and research efforts in various fields (Schiavo, 2014).

Thus, it can be said that the information seeking behaviour of parents of ASD children through virtual communities is a condition where they interact with each other, seek support and seek information in order to obtain solutions to the problems related to autism they face. Based on the explanation, this research aimed to understand the pattern of seeking information related to dietary interventions

for ASD children in a virtual community of parent support group in Indonesia.

## LITERATURE REVIEW

There is plenty research related to non-health information behaviour that had been carried out, one of this was research by Nurrahmi and Syam (2020) on student behaviour in dealing with hoaxes on social media using the information behaviour model from Wilson in 1996. Wilson's 1996 model was a revision of the model that integrates research from various fields outside information science, including decision-making studies, psychology, innovation, health communication and consumer research (Wilson, 1999, 2007).

The results of this study also indicate that passive attention and search behavior is the most dominant behaviour among college students (Nurrahmi & Syam, 2020). Based on this research, Wilson's latest model of information behavior also incorporates various elements beyond information, one of which is health communication.

## METHODS

This study used a qualitative approach. The subjects studied are virtual communities of parents who have ASD children. From the several virtual communities on Facebook, the most eligible for research is LRD Member Suar Autism. The reason for choosing this community is because of the large number of members (9,296 members as of May 13, 2019), the variety of topics of conversation around autism, as well as the suitability of the conversation topics with the substance of the research and the high number of uploads from community members.

In this study, the data collection procedure used was participant observation in the closed group LRD Member Suar Autism and interviews with community members. Interviews were conducted once, each with informants who were members of the community. Informant criteria were community members who was dieting for their children or who had positive experiences related to dieting in changing the behaviour of children with ASD.

The research method used is virtual ethnography, where data collection comes from the results of text observations produced by community members. Text content analysis was carried out on 178 uploads and 3,569 comments throughout August 2018. In addition, data collection was carried out through in-depth interviews with one of the admins and founders of the LRD Member Suar Autisme. In order to answer the research questions presented in this paper, NVivo 12 Pro is used for coding.

## RESULT AND DISCUSSION

### Virtual Community and New Media

Internet technology has created new media that have a positive impact on human life. New media makes interaction and communication easier without being hindered by distance and time. Schiavo (2014) mentions that new media has changed the way we view how we are connected to one another, which makes the role of new media increasingly in public health, health services and community development interventions. New media is a medium to expand ideas from the traditional to the elite of experts, connect individuals from various disciplines, and

create collaborations beyond geographical boundaries. This enables the creation of strong online communities, which help people cope with certain situations, enable them to do their jobs better and more effectively, and contribute to increased awareness of health knowledge and community development issues (Schiavo, 2014).

New media is useful for creating virtual support groups or virtual-based support groups for patients and their families. In the context of communication, each individual will be more easily connected to each other and allow each other to express opinions, exchange ideas and discuss various things. Then a discussion room emerged in the virtual world that bridged individuals from different backgrounds to share and exchange information.

Kozinets (2010) who summarizes various definitions of virtual community writes, the term virtual community refers to social aggregates that appear on the internet where discussions occur. The virtual community will form personal relationships in the cyber realm because it involves human feelings in it. Those in the online community argue with each other and exchange knowledge, and even share emotional support. In this context, the virtual community is a means for its members to interact with each other in a long discussion which in the end is able to form a network. However, the community itself does not actually have a fixed form, but consists of various choices of meaning negotiated by each individual. In this case individuals exchange ideas and interact. The interaction in question does not

only occur electronically, but can also be through face-to-face communication, or a combination of direct and electronic communication (Kozinets, 2010).

### Dietary Intervention Information Search Patterns in Children with ASD

Text analysis in this study focuses on how a text is responded to by community members and admins. From the results of observations about the text and interviews with members and admins to see the context of the text produced, it can be identified patterns of seeking information related to diet and food to help treat ASD children. The focus of the text observed is on finding information about dietary food interventions.

Based on conversation in the virtual community of LRD Member Suar Autism, the handling of ASD children through dietary intervention was one of the important things. Moreover, there had been many studies that mention the positive impact on the behavior of ASD children after the CFGFSF (Casein Free Gluten Free Sugar Free) diet. Although there are still pros and cons in the medical world regarding the implementation of the diet for ASD children, in the virtual community LRD Member Suar Autism dietary intervention was one element that is emphasized to community members to be carried out on ASD children. One of the reasons for the members to join this group is to seek information about how to implement a dietary intervention.

The CFGFSF diet is a pattern of regulating food intake by not consuming food or drinks that contain casein (milk

protein), gluten which is usually found in wheat flour and wheat, as well as sugar or sugar and all its derivatives. There are several studies which state that the CFGFSF diet has an effect on improving the behavior of ASD children.

In line with this, there are studies which state that individuals with ASD who follow a diet free of gluten and casein, curcumin, probiotics and fermented foods can reduce ASD symptoms, while consumption of sugar, additives, use of pesticides, genetically modified foods, food inorganic preparations and indigestible starches can exacerbate ASD symptoms (Cekici & Sanlier, 2017). Research reports that the use of a gluten-free diet is even more in Virginia, USA, which is 58.6% from 80.9% in complementary and alternative medicine (CAM) treatment (Hopf et al., 2016). While the phenol diet is a diet to avoid foods that contain high levels of phenols. For example, fruits with high phenol content are watermelon, banana, pineapple, papaya, red dragon. While vegetables that contain high phenol include carrots, kale, spinach. Both are included in the diet which is closely related to the regulation of food.

Discussions in the form of uploads and comments contained in the virtual community were mostly carried out by mothers. Without denying the role of fathers, mothers devote more time to their children and play a major role in seeking information and intervening for ASD children. The admin and founder of LRD Member Suar Autism is a mother, and another admin who is also active in answering questions is also a mother of an ASD child. Based on observations on

uploads and interview results, mothers play an important role in implementing diets for ASD children because mothers who make menus, decide to buy certain foodstuffs according to the CFGFSF and phenol diet and record the impact of certain foods on children. This requires extraordinary fighting power and resilience.

Based on the coding results, there are sub-themes related to diet, including food rotation, diet duration to how to start a diet. In table 1, you can see the data on the number of coding from the sub-themes about the diet. Based on table 1, it can be seen that the highest number of coding files is found in diet procedures with a total of 49 files and 86 references. This indicates that community members really need information about diet procedures, which include food rotation, dietary restrictions and how to start a diet.

Food rotation is related to changing the food menu every four days. The parents then recorded the effect of the food on the child's behavior. If after four days of eating certain foods the child experiences behavioral changes in a negative direction, for example tantrums, difficulty sleeping at night, rapid changes in mood (laughing or crying for no reason) then these foods must be eliminated and avoided for consumption by children. While dietary restrictions are also often asked by parents who are usually just starting a diet for their children. In addition to foods that contain casein, gluten and sugar, there are other foods that are not allowed to be consumed in the diet of ASD children, such as foods that are high in phenols. Doctors who recommend a diet usually recommend that a blood test be

performed on a child with ASD to confirm the food allergy suffered so that there are guidelines for parents of foods that can and cannot be consumed.

Unfortunately, the cost of blood tests is relatively expensive, so not all parents have the opportunity to do these tests for their children. Therefore, the principle of food rotation is carried out to record and observe foods that have a negative impact on children's behavior. This note then becomes the benchmark for parents to provide foods that are allowed to be consumed in their children.

Another thing that is often asked by parents is the problem when going on a diet, namely children who are picky eaters or picky eaters so that parents find it difficult to compose a diet menu, do not comply with the diet that is being run or leak diet or related to the level of compliance that is intentionally or accidentally eating taboo foods and implementing a diet when the child is sick. Of the three, the most frequently discussed is leaking a diet or not following the rules of the diet.

Given that children usually really like sweet foods, milk and all kinds of foods containing milk and its derivatives such as cheese, as well as snacks in the form of biscuits which are usually made from flour, diet leakage will be a problem that is often faced by parents. There are reports of parents who state that their children experience a decline in development or their child's behavior becomes bad when the diet that is being carried out is leaky or does not comply with the diet being carried out. This is in line with studies which state that ASD children get worse when their diet is leaked (Lucarelli et al., 1995).

**Table 1 The result of coding information exchange related to diet**

Theme	Sub Theme	Number of Files	Number of References
Type of Diet	CFGFSF	18	43
	Phenol	3	4
	Electronic	7	11
Total		28	58
Diet Procedures	Food rotation	18	28
	Food prohibition	24	48
	Starting diet	7	10
Total		49	86
Impact of Diet	Diet duration	4	5
	Positive impact	14	20
Total		18	25
Diet Problems	Picky eater	1	2
	"Leaky diet"	6	21
	Diet when sick	1	5
Total		8	28
Diet equipment	Cooking utensils	4	7
Total		4	7

Source: Document of Researcher

Based on the results of interviews with members of the virtual community LRD Member Suar Autism, they on average stated that when a child does not adhere to the diet that is being run or leaks a diet, bad behavior will appear triggered by the taboo foods consumed by the child. As expressed by Mrs. W, when her child disobeys the diet by eating Eid cookies, bad behavior such as laughing to himself or hurting himself by banging his head appears.

*«The effect is usually laughing, can be angry, banging heads. So it's better to have nothing at home, it's better to sacrifice at home there's nothing like that. If you have guests, that's fine, water.»*

Another mother, A, told of the development of her child who was very hyperactive since he woke up, and the dietary intervention had reduced his hyperactivity. She also said that her son progressed faster after going on a diet, it became easier to teach things, more focused and his vocals began to appear (started to be able to pronounce words) as in the following interview excerpt:

*“Even though my child is an active type, yes, he can still be directed. I feel that my child had a progress in his cognitive. For example, when we taught numbers, colours, the focus can be longer, even though there are other problems, yes, still. But the point is that before dietary intervention he didn't want to talk, now it's out, he can speak...”*

Meanwhile, L, an ASD child therapist, stated that ASD children who do not take dietary intervention will have an effect on behaviour, including being less calm, as expressed as follows:

*«But in my experience, yes, for those who didn't take dietary intervention, yes, it's all from God, but besides being slow, their behaviour was also less calm...»*

When these parents start dieting and need information about diet, they usually get information about Mrs. AS, founder of LRD Member Suar Autisme by word of mouth and then join the LRD Member Autisme to get more in-depth information about diet. They also asked Mrs. AS as the admin directly through their inbox about diet and got a positive enough response so that they later joined the LRD Member Suar Autisme. Meanwhile, L,

a therapist, found out about LRD Member Suar Autisme from a search on Facebook. The following is an excerpt from an interview with A, related to initially going on a dietary intervention because of a friend of her friend with ASD child. Then she tried to find more information about diet by reading and finally getting to know the admin of the LRD Member Suar Autisme.

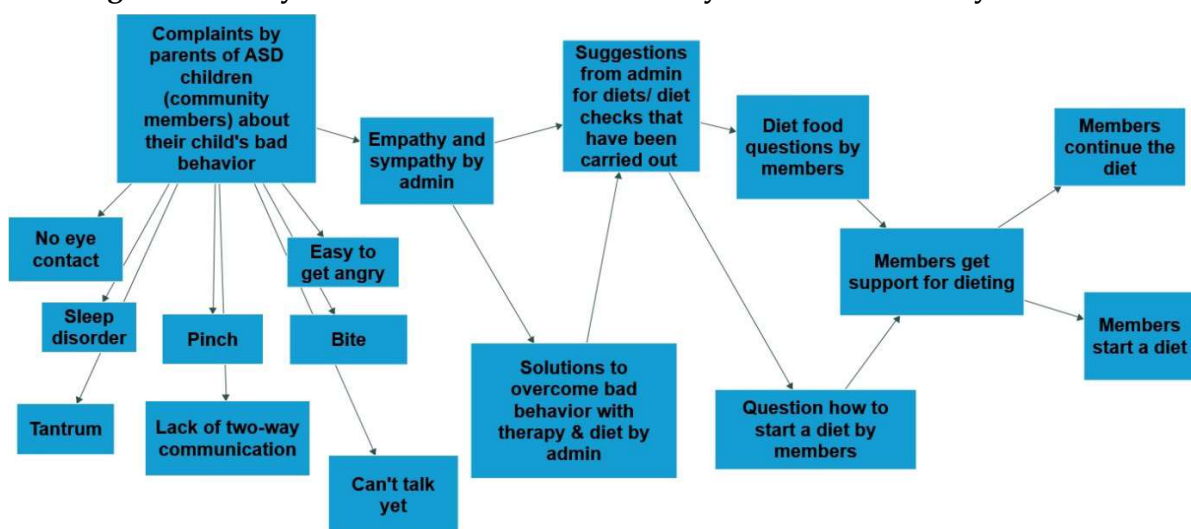
*«There are friends who have been on a diet too, I kept reading, and finally, yes, the problem increased (when I want to start dieting), that's why I first inbox with Mrs. AS (on Facebook) and was given initial guidance (to start dieting).»*

Based on the discussion above, it can be identified the pattern of seeking information about food diets by community

members, which begins with questions or seeking information on the following matter: Members' complaints about ASD children who behave badly, ranging from tantrums, lack of two-way communication, unable to speak, difficulty sleeping, biting, pinching, irritability, no eye contact; Members' questions about the procedure for implementing the diet; Questions about problems experienced when dieting, such as picky eaters, disobedience to the diet or diet leaks and how to implement the diet when the child is sick; and Questions about supporting tools, such as recommended cooking utensils to be used when cooking diet food.

The following is a chart of the pattern of searching for information related to diet carried out by community members.

**Figure 1 Dietary Information Search Patterns by Virtual Community Members**



Source: Documents of researcher

From Figure 1, it can be seen that the pattern of seeking dietary information by members of the virtual community began with parental complaints about their child's bad behavior such as no eye contact,

difficulty sleeping, tantrums, pinching, lack of two-way communication, unable to speak, biting and irritability. When parents as members of the virtual community upload these complaints, other members



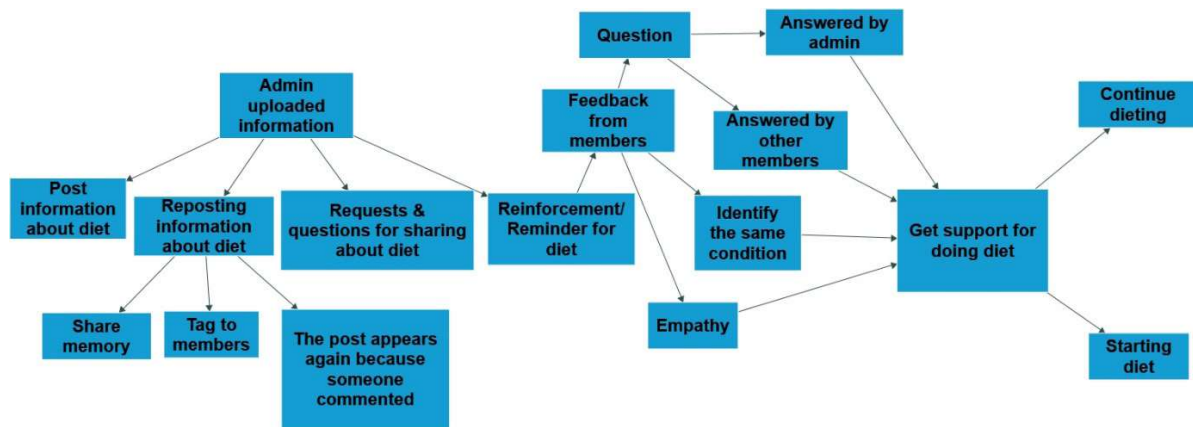
will empathize and then give suggestions to check the diet that has been carried out, whether it has been done correctly or not. Other members or admins can also provide solutions to overcome these bad behaviors by doing therapy, which is still balanced with diet.

When the member has been on a diet, then when it is recommended to check the implementation of the diet so far on his child, he will evaluate the diet that has been carried out; whether it is in accordance with the taboo and done by rotation. The next question that usually arises is what fruits or vegetables or food ingredients are allowed or not to be eaten. If the member has not been on a diet, then usually he will

ask how to start a diet. Other members and admins will usually answer how to start a diet. Admin will usually re-upload (repost) information related to how to start a diet. After feeling that they have the support to go on a diet, members who have not gone on a diet will start dieting. As for members who are already on a diet, they will continue their diet after evaluating whether the diet is correct or not.

In addition to the pattern of seeking information about diet by members of the virtual community, it can also be identified the pattern of presenting information about diet by the admin of the virtual community as shown in Figure 2.

**Figure 2 Pattern of Dietary Intervention Information by Virtual Community Admin**



Source: Documents of researcher

The presentation of information by the admin begins with four types of uploads, namely 1) uploading information about diet 2) uploading reposting information about diet 3) requests and questions to share about diet 4) reinforcements or reminder for diet. Especially for re-uploading information (reposting) the admin does by sharing memory, tagging members

for information, or old uploads can also reappear because there are members who comment on the upload. After presenting the information, feedback will appear from members in the form of questions about diet, which are usually answered by other members or can also be answered by the admin. In addition to questions, there is also the possibility for members to identify

the same situation regarding diet with uploads from admins. Another possible feedback is the emergence of empathy from other members towards a problem related to diet experienced by members. These various feedbacks lead to getting support for dieting, either continuing the diet for members who have already done it or starting a diet for members who have not gone on a diet.

The fulfillment for information becomes important when parents find their child diagnosed with a disease that is considered quite severe and has implications for long treatment, which may have to be done for life, such as in ASD sufferers. Starting from uncertainty when parents experience an ASD diagnosis in their children, the need for information is one of the keys to reducing this uncertainty. Furthermore, in the information search process, there are a series of patterns which, if examined further, are a form of interpersonal communication.

The communication that occurs between community members and fellow members and admins has its own characteristics, namely prioritizing the delivery of information support about handling ASD children, especially with regard to dietary intervention and psychosocial therapy followed by the provision of emotional support. This is in line with the theory of interpersonal communication related to health and computer-mediated. Schiavo (2014) states that through computer-mediated interpersonal communication, it allows one to discuss sensitive issues, connect with others who have similar health problems,

network and learn about the latest treatment solutions. In this study, the common health problems experienced by parents of ASD children are the main factors that cause parents to join virtual communities to seek information more intensely by conducting interpersonal communication with fellow community members and admins.

In the context of health communication, when a community member adopts the information provided by both the admin and fellow community members regarding the intervention of ASD children through diet, a series of processes are needed and the process involves many factors, including social support and the ability and confidence to be able to do things. This is in line with the Ideation Theory, which states that health-related behavior is influenced by various factors. These factors are knowledge, attitudes, self-image, perceived risk, norms, self-capacity, emotions, social support and influence, and personal advocacy (Kincaid and Figueroa, 2004 in Schiavo, 2014).

This study also relevant with the previous study about parents of ASD children in seeking behaviour in Edmonton, Canada, and Egypt. In Edmonton, Canada, parents mostly rely on medical professionals and the Internet for information. Other sources of information include nonprofit organizations, government agencies, libraries, conferences and seminars, printed materials, and newly diagnosed parent meetings. However, the results show a growing reliance on parental support systems on social networking sites, such as Facebook, that allow parents to connect and share helpful information about parenting of ASD children (Beesoon, 2015).

Meanwhile, in Egypt, the information-seeking behavior parents of ASD children used many types of information, which varied between formal and informal sources. More than three-quarters of them used informal sources, such as mobile/smartphones, the Web, social media and social networking sites (Mansour, 2021).

## CONCLUSION

The pattern of seeking information about dietary intervention by community members begins with questions or seeking information regarding the following matters: Members' complaints about ASD children who behave badly, starting from tantrums, lack of two-way communication, unable to speak, difficulty sleeping, biting, pinching, irritable, no eye contact; Questions from members about the procedure for implementing the diet; Questions about problems experienced when dieting, such as children who are picky eaters, disobeying the diet or leaking diet and how to implement the diet when the child is sick; and Questions about supporting tools, such as recommended cooking utensils to be used when cooking diet foods. Meanwhile, the role of dietary food for handling ASD children is to improve the negative behavior of ASD children, including improving focus, making it easier for children to understand commands, and reducing tantrums. Diet must be combined with psychosocial therapy so that the results obtained are more optimal.

It can also be identified patterns of presenting information about dietary intervention by admins starting with four

types of uploads: uploading information about diet; reposting information about diet; requests and questions to share about diet; and reinforcement or reminder for diet.

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