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Institute of Metallurgy and Ore Beneficiation, Satbayev University, Almaty, Kazakhstan

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Fatma Fauzia

Universitas Muhammadiyah Yogyakarta, Indonesia

E-mail: fatma.fauzia.fkik20@mail.umy.ac.id

ORCID ID 0000-0003-3815-0816

Ahmad Madani

Universitas Muhammadiyah Yogyakarta, Indonesia

E-mail: ahmad.madani.fkik19@mail.umy.ac.id

ORCID ID 0000-0001-6474-7275

Sarah Zulaikha Samad

Universiti Sains Islam Malaysia, Malaysia

Parents' knowledge of graves' disease as an autoimmune disease among children

Abstract: Grave's disease is a relatively rare disease in the pediatric age group when compared to adults. Based on epidemiology data, only 0.1 – 3 per 100,000 children have this incidence. Although it is a rare disease, it has great consequences. Hyperthyroidism can result in weight loss, decreased concentration, and school performance, and may even consequently lead to a thyroid storm. Since it is an uncommon disease, there is little research about Graves' disease, especially about parents' knowledge regarding the disease. This article is purposed to determine the views of the knowledge of parents as guardians of their children using the phenomenology study design. To collect the data for this qualitative research, a total of 5 parents were interviewed. The research findings from the interviews showed that parents have poor knowledge of Graves' disease and its autoimmune cause. Nevertheless, parents understood how to act in conditions that their children might encounter. The findings indicate that more steps need to be made to educate parents on the causes and consequences of the disease.

Keywords: graves' disease, parents' knowledge, children's autoimmunity.

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Introduction

Graves' disease is an autoimmune disease that can affect anyone. The initial consequence of Graves' disease is hyperthyroidism. Linguistically, hyperthyroid is defined as too much thyroid hormone. If the amount of thyroid hormone in the body is above normal or too high, the function of the organs associated with the hormone will be problematic. This is called the phenomenon of thyrotoxicosis, which is a clinical manifestation of too much thyroid hormone. Symptoms that appear can include enlargement of the thyroid gland/goiter, heart rhythm disturbances, fever, weight loss, and bone loss (Nugraha & Samodro, 2019). If this happens without further treatment, the quality of life of an affected person can decrease, until at worst it leads to death.

Epidemiologically, Graves' disease is very rare. In one data, graves' disease occurs in 0.1-3 per 100,000 children (Lee & Hwang, 2014) with a peak incidence in children aged 10-15 years and is very rarely found in children under 5 years. Other risk factors include women, early reproductive age (age 10-15 years), and people with a family history of Graves' disease (Yati et al., 2017). Although not all thyrotoxicosis is caused by hyperthyroidism due to Graves' disease, hyperthyroidism alone has epidemiology of 70% of all

cases of thyrotoxicosis in the world, meaning cases of hyperthyroidism regardless of Graves' disease or not, are considered serious cases to be treated (Srikandi, 2020).

Several studies have been conducted regarding Graves' disease in children. These studies have explored the incidence of graves' disease in children, effective treatment, complications of graves; disease, as well as the risk and etiologic factors of Graves' disease (Nugraha & Samodro, 2019; Srikandi, 2020; Subekti & Pramono, 2018; Yati et al., 2017). However, research related to parental perception of this disease has not been carried out.

It is undeniable that parents are the first people who are directly related to the child, especially if the child and parents live together in the same house. Thus, this research study is needed to determine the views of the knowledge of parents as guardians of children which can be the main prevention of complications and death of children due to Graves' disease. This research was conducted to answer about how parents know about graves' disease, how parents know about autoimmune disease, whether parents are aware about graves' disease as an autoimmune disease in children, and what parents can do to avoid the disease in their children.

Theoretical Framework

Naming of Graves' Disease

Robert Graves is the discoverer of the relationship between the symptoms of thyrotoxicosis, namely enlargement of the thyroid gland, palpitations, and exophthalmos. This set of symptoms was further investigated by scientists after Robert Graves, then it was concluded that the findings of this relationship were the result of auto-immune disease from TSH. Graves' name was taken as the name of Graves' disease (Smith & Hegedüs, 2017).

Graves' Disease as Autoimmunity

As an autoimmunity, Graves' disease is not a disease that can be completely treated until the root cause of Graves' disease has disappeared. However, with proper and regular treatment, patients with Graves' disease have a good prognosis (Srikandi, 2020). In recent years, a study regarding checkpoint inhibitors for graves' disease has been found. Anti-PD-1 could be an induced treatment for autoimmune hyperthyroidism, which is grave's disease (Brancatella et al., 2019).

Pathophysiology of Graves' Disease

Thyroid stimulating immunoglobulin (TSI), also known as thyroid stimulating antibody, causes Graves' disease (TSAb). Thyroid stimulating immunoglobulin is mostly produced by B lymphocytes in thyroid cells, but it can also be produced in lymph nodes and bone marrow. T cells that have been sensitized by antigen in the thyroid gland stimulate B lymphocytes. Thyroid stimulating immunoglobulin attaches to the thyroid-stimulating hormone (TSH) receptor on the cell membrane of the thyroid gland and stimulates the hormone's function. It causes hyperthyroidism and thyromegaly by stimulating thyroid hormone synthesis and thyroid gland growth (Subekti & Pramono, 2018). The pathogenesis that explains the contributing factors of hyperthyroidism in graves' disease were because post-partum state, tobacco smoking, and physical or emotional stress (Burch & Cooper, 2015).

Thyrotoxicosis

Thyrotoxicosis is a condition in the form of clinical manifestations of the state of too much thyroid hormone in the blood. Thyroid hormone with normal levels has many functions for the body, including regulating metabolic functions in various organs. However, if the amount of thyroid hormone is excessive due to hyperthyroidism, the nature of thyroid hormone can be dangerous or in other words "toxic" because the body's metabolism is not controlled. This is what causes the symptoms of thyrotoxicosis such as weight loss, faster heart beats, tremors and body shaking, weakness, difficulty sleeping, can't stand heat, excessive sweating, and frequent bowel movements (Subekti & Pramono, 2018).

Parents' Roles in Children Health

Parents, as we know someone who has been with their children most of the time have the obligation to keep the children in good condition. This statement was implicitly stated in the journal "The

Role of Parents in the Community Health Program". According to the journal, parents have three main essential responsibilities in relation between children and their health, which is maintaining the improvement of parent's own health, maintaining the improvement of children's health, and utilizing the quality of the public health program provided (Veselak, 1958).

Empirical Review

Research regarding the epidemiology of graves' disease has been made through the years. Findings of the epidemiology could lead to the fact that graves' disease is a dangerous and menacing disease to the children. Ni Made Putri from Interna Medicine Department Bhayangkara Hospital in 2020, in her study entitled "Hipertiroidisme Graves' Disease: Case Report" explained not only the epidemiology, but also explained the complication in a detailed way about graves' disease. This study offered information about graves' disease's case report in the Bhayangkara hospital and said that Graves' disease could lead to thyrotoxicosis which is very dangerous to whoever is diagnosed with graves' disease.

Another study entitled "Current Diagnosis and Management of Graves' Disease" written by Imam Subekti from Faculty of Medicine Universitas Indonesia in 2018 focused on the pathophysiology and ways to diagnose graves' disease. This study highlighted the understanding, the clinical point, and the prevention of the relapse by gathering the results of grave's disease studies. One of the findings is that patients with graves' disease could have relapsed after stopping the anti-thyroid drugs given by the physician.

Both studies mostly wrote about the explanation of Graves' disease without any other actor involved in the graves' disease. Study related to the parents' knowledge towards graves' disease as autoimmunity on children has never been conducted prior to this. This study is focused on the knowledge of parents about graves' disease that made some decisions if they found out about the symptoms in their children.

Research Methods

This research was conducted with a qualitative method to determine the knowledge of parents on Graves' disease that may occur in their children. To obtain research data, researchers conducted direct interviews with in-depth questions were asked. Participants as interviewees of this study were parents who had children from Sawo, Dusun Glondong village area. Researchers as interviewers went door-to-door to collect the data from interview. Data saturation was found from the fifth interviewee, with the total of the participants were 5 parents, including one of them which is a single parent.

The interview questions that were previously made by the researcher contained questions related to the knowledge of parents about Graves' disease and how parents are aware about the disease. Some additional questions related to the knowing of parents will also be asked as material for obtaining more accurate data.

To the participants, it was conveyed that all matters discussed were only for research purposes. All participant identities are kept confidential. Everything that was informed by the participants did not affect anything related to the participants' future.

Researchers directly came and then interviewed the participants, after the participants have agreed to be used as research sources in informed consent. It also conveyed that all topics discussed were for research purposes only. Each participants' identities remain confidential. All things informed by participants do not affect anything related to them. Avoiding bias was done by confirm the interview result to the interviewee. After data collection, the researcher classifies the questions and analyze the data that has been taken. Finally, conclusion was made regarding the parents' knowledge on Graves' disease. There are 2 variations of the selected field, there are the titles and abstracts of the mapped research.

Instrument Design

1. What do you know about the cause of graves' disease?
2. What do you know about some autoimmune disease in children?
3. What will you do if there are some suspicious symptoms on your children?

4. How do you think the importance of parents' role towards children's health related to grave's disease?
5. What efforts have been made by parents to protect their children from autoimmune diseases, especially grave's disease?

Research Results

Basic Knowledge

This heading is the findings of the questions: (1) What do you know about the cause of graves' disease?; and (2) What do you know about some autoimmune disease in children?

Based on all the respondent we have interviewed, most of them do not know that Graves' disease is an autoimmune disease in children. Instead, most of them mentioned other autoimmune disease in children, such as diabetes and lupus. Nevertheless, they just mentioned it without knowing any further explanation regarding the disease. There is also respondent who mentioned autoimmune disease that unlikely happened in children, which is rheumatoid.

What is Graves... maybe it's a kind of immune-immune disease... the point is um... basically red blood cells, uh, white blood cells themselves attack themselves...

To be honest, I just heard the name of this disease, so I don't even know what it is (about the disease).

The statements written proves that most of our respondent are now aware of Graves' disease. They only learnt about the disease during the questionnaire. Only one respondent mentioned that Graves' disease is something related to autoimmunity. However, the respondent could only explain about the autoimmunity as something that attacking the children's own bodies.

To explore their knowledge on autoimmune disease, the respondents were asked to list other autoimmune disease except Graves' disease

I know that diabetes mellitus is type 1, it attacks small children.

Maybe just knew about diabetes from autoimmunity, and lupus, and one again rheumatoid.

Parents are aware that diabetes, lupus and rheumatoid are autoimmune diseases. Nonetheless, none of them knew that Graves' disease was also an autoimmune disease. It means that Graves' disease is not a familiar disease compared to other autoimmune disease in children.

Parents' Roles

This heading is the findings of questions: (3) What will you do if there are some suspicious symptoms on your children?; and (4) How do you think the importance of parents' role towards children's health related to grave's disease?

This big theme of parents' roles is to understand how was the parents' attention toward their kids to overcome their children's health problems.

We gave them a case where their children witness the grave's disease symptoms. All the respondent answered the same that they all will bring their children to the hospital to get diagnose and treatment. One of our respondents answered that bringing their children to the doctor is one of parents' obligations to take, according to what Islam religion mentioned.

Oh yes, if it's too suspicious, yes, of course, I will take it to the doctor. Because Islam also recommends "fas-alu ahl al-dzikri in kuntum la ta'lamun" so ask someone who has knowledge if you don't know. So, in terms of health, the one who knows the science is the doctor. So, Inshallah I will go to the doctor.

Answering the question whether parent's roles is important, parents as respondents told us that it is. Not just specific in grave's disease but include all of health problems to avoid children's health inconvenience.

Of course, it's important, Ms. We as parents know about what our child is feeling, for example a fever or something like that. The problem is that parents are the closest friends of children, especially if you don't use a sitter. At least we know that if the child is sick.

As parents, you must ask a lot of questions to your children because sometimes the children don't admit. As a parent, you really must monitor everything, you must find out, ask questions,

remember, that's what you have to do. Even though sometimes we have to fight with children, we are fussy for good.

We could see the fact that parents said implicitly that it is important for parents to keep an eye on their children because they are the only one who probably known about what's wrong even sometimes the kids do not tell about it.

Effort and Protection

This heading is the findings of questions about what efforts have been made by parents to protect their children from autoimmune diseases, especially grave's disease.

Every parent we asked answered that they have done so many things to protect their children from any of the disease could be gotten.

From being pregnant with the child, sis, so when I was pregnant, my consumption of food was regulated. Then after birth, um... we are responsible as parents by giving good nutrition to our child... then... maybe from breast milk if I give breastfeeding 2 years, then we can adjust o according to food our child at that time

When I eat, I really have the concept of eat, eat, eat. You don't have to remember the nausea, you don't have to remember the dizziness, you don't have to remember the vomiting. That's why all my babies that were born weighed 3 coma and above. The minimum is 3.1.

From what being said, the parents we interviewed were aware of prenatal nutrition as a factor in preventing disease by maintaining health since the child was still in the womb.

In addition to nutrition, vitamins, good parenting keeps you from falling even while exercising. Immunizations are also complete. Like it was looked after, well cared for. That's one of the strategies so that its growth and development is maintained properly. From physical and mental.

Not only during pregnancy, but adequate nutrition for children is also known by parents as important for growth and development in children which can lead to disease prevention.

Research Discussions

Our study showed that most of parents who became our respondents didn't know about Graves' disease, even never heard of it. This gives us understanding that our respondents do not have any proper knowledge regarding children's autoimmune disease, specifically Graves' disease. Nevertheless, respondents have a good understanding about awareness towards children's health and children's nutrition. The findings were supported by the interview results that they mention their concern related to how they overcome children's health problems and children's daily dining.

In the literature review that has been carried out, autoimmune diseases, especially Graves' disease, have symptoms of thyrotoxicosis which are very dangerous for the patient. Unfortunately, the knowledge of parents about this disease in the areas of Wirokerten, Banguntapan, Bantul, Yogyakarta is very poor and inadequate. In addition to being supported by the results of interviews, this statement is also supported by journals which stated that autoimmune diseases can be told to be unacknowledged disease, especially in developing countries, one of which is Indonesia. This is due to a lack of understanding related to autoimmune diseases due to lack of education, information, and counseling to the general public (Azwinda, 2020).

Associated with the essential three things of parent roles towards their children in the journal of "The Role of Parents in the Community Health Program", parents where this research takes place, have been at least complete two out of three obligations. Both of them are maintaining the improvement of parent's own health and maintaining the improvement of children's health (Veselak, 1958). As for utilizing the quality of the public health program provided, need to be improve to the fact that there is lack of education towards graves' disease on interviewed parents.

Conclusions

This study that surveyed about parents' knowledge towards grave disease as children's autoimmunity, specifically discuss regarding the parents' basic knowledge, parent's roles, and parent's

effort and protection was conducted to five parents in total as our respondents. The respondents were picked from surroundings area of Ponpes Jamilurrahman, Glondong, Wirokerten, Banguntapan, Bantul, Yogyakarta. The results of this research are parents have bad knowledge towards grave's disease as children's autoimmunity. But at the same time, parents understood how to act and to do in every bad condition their children might encounter related to their health problems.

This study shows that health knowledge and education need to be escalate on parents. The more parents understand and know about all of children's autoimmunity, the more parents will acknowledge how crucial autoimmunity on children can be.

This study that has been made through interview method was lacking in the quantity of parents as respondents. Further research towards the same issue is necessary to get data related to how much parents that know about grave's disease as children's autoimmunity.

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