

Special Months for Special Needs Children

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SPECIAL MONTH FOR SPECIAL NEEDS CHILDREN

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ABSTRACT

Down Syndrome is one of the most commonly found genetic conditions, a chromosomal abnormality that is. It is caused by an extra chromosome 21 in their body. The extra chromosome itself can be a total chromosome 21, or just part of it. Whatever the form is, it leads to distinct physical features along with associated medical conditions. One of the symptoms of people with Down Syndrome is the cognitive problem where all of them would have various levels of intelligence, making the learning and comprehension process challenging. For Muslims all around the world, Ramadhan is the one special month of the year where everyone would fast. Learning about Ramadhan and conducting fasting during Ramadhan could be challenging for children with Down Syndrome. There is no known absolute contraindication for them to fast, but several comorbidities related to the condition might hinder them from doing fasting. This short communication paper provides brief review on Down Syndrome and what are the possible challenges that people with Down Syndrome would face during Ramadhan.

Keywords: Down Syndrome, Ramadhan, Special Needs Children

1. INTRODUCTION

Based on data from According to the *World Health Organization*, the incidence of Down's Syndrome worldwide is estimated at 1 in 1000 to 1 in 1100 live births.¹ In Indonesia alone, the number of people with Down Syndrome based on Sistem Informasi Rumah Sakit (SIRS) in 2017 reached 4130 cases.² There is no racial or gender predilection in this syndrome. However, it is known that the prevalence of Down's Syndrome increases with the age of the mother. The older the mother at delivery, the more likely she is to have a child with Down Syndrome.³

Down syndrome itself was first described in 1866 by an English doctor named John Langdon, although its association with chromosome 21 was only proposed nearly 100 years later by dr. Jerome Leujene in Paris.¹ Down syndrome itself is a genetic disorder – in this case, Chromosomal abnormality, that is commonly found.⁴ Under normal circumstances, every man has 46 chromosomes or 23 pairs of chromosomes. People with Down syndrome have extra chromosome 21 on their body thus also known by the term trisomy 21. This extra chromosome 21 could occur in total or partial. Whatever form it takes, this extra chromosome 21 will be causing various health problems for individuals suffering from it. Take, for example, intellectual disability, impaired growth, congenital heart defects, leukemia, to various health issues that can arise at adult age.⁵

These health problems could affect their quality of life, signifying the importance of early screening and management. Therefore, early identification of Down Syndrome is important for minimizing health problems that would possibly arise. What is equally important is the process of education and counseling to families regarding the condition. Included in the education and counseling is also how children with Down Syndrome can be taught and trained on certain matters to a certain degree. For Muslim parents and families, this means that they can try to actively teach, introducing Ramadhan to a family member who is affected by Down Syndrome. Not only introducing, but families can also try to train them how to fast during Ramadhan, with several things to consider. This narrative review provides a brief description of Down Syndrome in its relation to the holy month Ramadhan.

2. DISCUSSION

4 CAUSES AND TYPES OF DOWN SYNDROME

Down syndrome is caused by an error in the process of cell division, either in mitosis or meiosis. In general, most Down syndrome is caused by the presence of trisomy chromosome 21 in the sufferer. However, Down syndrome can also be caused by mosaicism and translocation of chromosome 21. Regardless of the cause of Down Syndrome, it is important to remember that each person with Down Syndrome will have an extra chromosome 21. This extra genetic material is what gives rise to all the clinical characteristics found in Down Syndrome patients.^{1,5} Furthermore, this extra chromosome 21 can be found either in all body cells or only in some cells (mosaicism). The incidence of mosaicism in Down syndrome cases is rare, only found in about 1 to 2% of the total cases. Some research indicates that patients with Down syndrome with mosaicism type will have milder clinical symptoms than patients with classic or translocation type. In translocation type, the number of chromosomes will still be 46, because there is only an extra part of chromosome 21 and not an extra

chromosome 21 as a whole. Even so, this extra part of chromosome 21 will still result in a typical clinical picture of Down Syndrome.^{1,5}

PHYSICAL CHARACTERISTICS OF DOWN SYNDROME

Alleged diagnosis of Down Syndrome can be made as early as possible immediately after birth only based on the physical appearance of the baby. Many distinctive physical characteristics can be found in infants or children with Down Syndrome that can help in establishing a suspected diagnosis of Down Syndrome. However, some of the physical features of Down Syndrome can also be found in the normal population in general. Therefore, it is necessary to examine chromosome analysis to establish a definite diagnosis of Down Syndrome. It should be noted that the clinical findings of one patient with Down Syndrome will not always be the same as that of another patient. Some of the typical physical characteristics of people with Down Syndrome are as follows: (1) Decreased muscle tone where muscle will feel mushy, (2) Facial profile that tends to be flat; base nose flat and relatively small nose, (3) corners of the eyes that tend to rise, (4) abnormal ear shape, (5) Simian crease in the palm of the hands, (6) Very flexible joints, (7) Curvature on the fifth finger, (8) Epicanthic folds, (9) The wide distance between the thumb and index finger of the toe, and (10) A relatively large tongue, making their mouth open and the tongue sticking out.^{1,5} In addition to the physical characteristics that are visible to the naked eye as mentioned above, people with Down Syndrome also experience structural and functional abnormalities in their bodies. Problem The health conditions that are commonly encountered vary from hearing loss (60-80% of cases), congenital heart defects (40-45%), intestinal disorders, visual system disorders, etc.¹

LIFE EXPECTANCY

The life expectancy of people with Down syndrome varies greatly depending on the possible complications that arise in the sufferer, such as congenital heart defects, susceptibility to infection, to the incidence of leukemia. In the early 1900s, Down syndrome patients were only able to survive to the age of under 10 years. As of today, as many as 80% of people with Down Syndrome can survive to the fifth decade of life or more. Down syndrome patients can live their lives optimally with the support of their family, community, and monitoring of their health, both physically and mentally. In addition, it is necessary to carry out physiotherapy, counseling, and a special/inclusive education system.¹

RAMADHAN AND DOWN SYNDROME

The holy month Ramadhan is the most awaited month by Muslims all over the world, where Muslims will conduct fasting for the whole month. For children with need special like people with Down syndrome, the meaning of Ramadhan and the series of activities that entail might be challenging to comprehend. Despite the possible challenges that people with Down Syndrome and their family would have to cope to during Ramadhan, there are no articles specifically discussing on this matter. Hence, the lack of references.

As mentioned above, people with Down syndrome will have cognitive problems, with various levels of intelligence, so they will experience difficulty in learning and understanding something. However though their level of intelligence is below average, people with Down syndrome can be taught and trained to a certain extent. Their ability to understand or recall

can be trained through a series of stimulation done continuously. In relation to Ramadhan, introducing the holy month Ramadhan to them so that they are aware of the difference between Ramadhan and the rest of the months can be done by continuously introducing and explaining what it's Ramadan, and what is so special about the month. When they already know about Ramadhan, the next step would be to inform them about what are the special things we do every Ramadhan, including fasting. Regarding their condition, there is no absolute contraindication for them not to fast during Ramadhan. Nevertheless, there are a few things to consider for people with Down Syndrome before they decide to do fasting. One thing to highlight is *feeding difficulty* and dysphagia, which are commonly found in people with Down Syndrome. These conditions are thought to be caused by decreased muscle tone, and lack of oral sensorimotor in Down syndrome. As a result, people with Down syndrome can experience choking, coughing, difficulty in chewing, to an aspiration that is life-threatening. Considering the feeding and swallowing difficulty possibly experienced by people with Down syndrome, parents or caregivers need to be able to recognize and identify whether their children are having the complaints or not. If they find out that their children are experiencing one, intervention and management should be done. One example of the interventions is by introducing different food textures to them.⁶

3. CONCLUSION

Ramadhan is the most awaited month for Muslims offers a special nuance and its presence is a blessing to all Muslims. Muslims with Down Syndrome can also be participating during the month with several concerns. Before involving them in the special activities during the month, families need to introduce and explain Ramadhan and its characteristics repeatedly as people with Down syndrome have difficulties in learning. Fasting can also be done by people with Down Syndrome as long as they are not having certain comorbidities or medical conditions that prevent them from doing so.

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