

**Education on Nutrition and Seizure Control in Children with Cerebral Palsy
for “Mitra Ananda” Community Organization in Gunungkidul, Yogyakarta, Indonesia**

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Abstract

Persons with Cerebral Palsy (CP) have disabilities due to disorders of the musculoskeletal system that were often accompanied by various other symptoms with different degrees of severity, such as seizures, intellectual disabilities, bone deformities, learning disorders, etc. Those people have a higher risk of malnutrition and seizures, especially children with CP. Mitra Ananda is an organization of parents of persons with CP that aimed to empower families of persons with CP Gunungkidul Regency. Understanding of a problem, knowledge of the solution, and confidence to implement the solution are the keys to creating an empowered community that will later become a driving force to empower others in health issues. Education on nutrition and seizure control was delivered through presentations and discussions to the members of the Mitra Ananda Organization. Program evaluation was carried out quantitatively and qualitatively. A questionnaire for the quantitative method was developed to assess caregivers' knowledge of nutrition. The assessment results presented increased knowledge of the beneficiaries. Focus group discussions and interviews showed changes in attitudes and behavior on nutrition and seizure control. Mitra Ananda members who were also caregivers of children with CP shared the newly acquired knowledge with other members. In addition to the multiplication effect, it also creates a community that becomes a driving force to empower others.

Keywords: Cerebral Palsy, nutrition, seizures

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Introduction

Cerebral palsy is a heterogeneous disorder of movement and posture that has a wide variety of presentations, ranging from mild motor disturbance to severe total body involvement (Azar et al., 2016). Cerebral palsy was an umbrella term encompassing a group of non-progressive, noncontagious neurological conditions that cause physical and cognitive disability in human development, in which functional performance, participation, movement, strength, posture, muscle tone, sensation, vision, perception, communication, and behavior can be affected. Cerebral palsy was caused by damage to the motor control and cognitive centers of the developing brain and can occur during pregnancy (approximately 75 percent), during childbirth (approximately 5 percent), or after birth (approximately 20 percent) (Thorngren-Jerneck & Herbst, 2006). Persons with Cerebral Palsy are included in the disability category because they have disorders of the musculoskeletal system and are accompanied by various other symptoms depending on severity such as seizures, intellectual disabilities, bone deformities, learning disorders, and so on (Frontera, et al., 2018). Children with Cerebral Palsy have a higher risk of experiencing malnutrition so the needs of a person with Cerebral Palsy must be monitored in terms of their nutritional needs so that difficulties related to meeting daily nutrition can be quickly resolved (Irish Nutrition and Dietetics Institute, INDI, 2015).

Based on the 2010 Basic Health Research report by the Ministry of Health, the Research and Development Agency showed the prevalence of Cerebral Palsy in Indonesia was 0.09% in children aged 24-59 months. According to the data from the Central Statistics Agency, the percentage of malnutrition in children, especially in Gunung Kidul, was 0.53%, and malnutrition

was 6.55% (Badan Pusat Statistik, 2019). Seizures were common in children with Cerebral Palsy with rates varying from 15 percent to 60 percent (Gürkan, et al., 2018). The Central Statistics Agency found that services were still limited in relation to Cerebral Palsy in Gunung Kidul. The rapid assessment of the impact of Covid-19 on persons with disabilities and their caregivers done by the DPO national network for Inclusive Covid response (2020) showed that persons with disabilities had increased significant barriers in finding personal assistance, difficulty in accessing therapy services, reduced income, difficulties on meeting basic needs and difficulties in health services due to Covid-19 (DPO National Network for Inclusive Covid 19 Response, 2020). Efforts needed to be made to address the impact of Covid- 19 on children with Cerebral Palsy especially in addressing challenges in nutrition and seizure management.

Mitra Ananda was a subsidiary of 19 organizations under a community empowerment organization, namely Mitra Sejahtera Disability Empowerment Center (PPDMS= Pusat Pemberdayaan Disabilitas Mitra Sejahtera) located in Nglipar Village, Gunungkidul Regency. Mitra Ananda had a membership of 50 persons whose family members or children had Cerebral Palsy. From the field discussions conducted both online and offline with them (mostly the mothers of children with Cerebral Palsy), the caregivers wanted to learn and know how to meet the nutrition requirement for children with CP, symptoms that could affect the children's condition, medications advised for managing digestive system disorders. There were limited services related to Cerebral Palsy and there was no pediatrician at the nearest community health center (Puskesmas). The discussion led to an agreement to provide health education on nutrition and seizure management of children with CP for the members of Mitra Ananda.

Experimental Details

According to WHO, community empowerment enables communities to have more control over their lives (WHO, 2009). The project empowered the community by increasing the knowledge of the parents of children with cerebral palsy. The increased knowledge of fever and seizures was expected to enable the parents to have more control over what to do when their children have fever or seizures. There were five principles of community empowerment, they were community control, public sector leadership, effective relationships, improving outcomes, and accountability (Strategic Scrutiny Group, 2019). The project applied these principles, particularly the first one in which the parents of children with cerebral palsy have more control over their decision regarding their children's health condition.

The community empowerment program had the following steps:

1. Preparation step

- a) January 2021, a discussion with members of the UKDW service team was held to discuss the objectives, goals to be achieved, and the topics that would be raised on the date. After that, an online joint meeting with the chairman of the PPDMS on January 13, 2021, to get to know more closely with Mitra Ananda members was carried out.
- b) February 2021, the service team took the second stage of preparation through a field visit to obtain information and assessed real conditions in the field. Moreover, the team observed the situation as well exploring further needs of Mitra Ananda members.
- c) March 2021, the service team planned the schedules, tasks division, education materials on nutrition and seizure management, files such as attendance list and MoUs as well as transportation.

2. Implementation step: The community program was carried out starting with an introduction to caregivers of CP at Mitra Ananda and followed by health education on nutrition and seizure management for children with Cerebral Palsy.
3. Evaluation step: The evaluation methods were quantitative and qualitative.
 - a) Quantitative method: knowledge or understanding of education's participants were measured by pre and post questionnaires which have been prepared by the University service team upon consultation with them.
 - b) Qualitative method: focused groups discussion with CP caregivers at Mitra Ananda was conducted. The time gap between the health education and the second discussion was within one month.

Results and Discussion

Mitra Ananda members carried out regular meetings in which they supported each other and brought their homemade products such as salted eggs, snacks, crafts, and merchandise for selling or exchanges. However, since the spread of Covid-19, they reduced the meeting span from monthly meetings to three-monthly meetings due to Covid-19 protocols. The Covid-19 pandemic had affected community meetings (Ebrahim et al., 2020). People were forced to minimize crowd size, reduce gathering frequency and practice social distancing (Reuben et al., 2021). Some research on the community behavior of related to covid-19 reported that Indonesian people were quite disciplined to the health protocols (Yanti et al., 2020). Mitra Ananda members reduced their meeting frequency and compensated for the meeting gap by intensifying communication in the WhatsApp group.

The community service activities in the form of health education started with assessment and preparation from January – March 2021 and were followed by the implementation from

April to June 2021. The first socialization was attended not only by Mitra Ananda's members but also by the committee of 18 other organizations under PPDMS. It was initiated by explaining the program's context and objectives. During the first socialization, the socio-economic conditions of parents/caregivers were observed because the research of de Andrade (2017) revealed that the guidelines received by parents needed to be adapted to the environment and local context of each child and family.

Respiratory dysfunction is a leading cause of morbidity and mortality in individuals with cerebral palsy (CP). In children and adults with CP, movement and physical function are always affected. Children with cerebral palsy have an increased risk of sudden death during sleep (Proesmans, 2016). In particular, recurrent aspiration, impaired airway clearance, spinal and thoracic deformity, impaired lung function, poor nutritional status, and recurrent respiratory infections negatively affect respiratory status (Boel et al., 2019). In addition, we know that advanced age and pre-existing respiratory comorbidities are significant risk factors for respiratory complications from Covid-19. So, if a person with CP catches Covid-19 and develops respiratory symptoms, they should be informed that they could be at a higher risk of developing severe respiratory symptoms (Brandenburg et al., 2020).

The following educational session was in form of a group discussion, in which the University team delivered educational materials through a power-point presentation and a question and answer session. The interaction and discussion with the participants were intense. The education materials included daily nutritional intake, consequences if their nutritional needs were not met, some forms of seizures, symptoms that often accompany seizures, things to do and not do when children have seizures, and education related to eating disorders and how to reduce constipation complaints in CP children. The materials and discussion lasted for 3 hours.

Malnutrition was one of the conditions often suffered by people with CP because it increased the risk of growth failure (Sadowska et al., 2020). Eating disorders were often experienced by people with CP which affected the amount of food that could be consumed by people with CP. The eating disorders found in people with CP included the inability to feed themselves, inadequate/absent lateralization of the tongue, chewing problems, swallowing problems, coughing/choking while breastfeeding, salivation, inability to eat solid foods, constipation, vomiting/regurgitation, and inappropriate wide mouth opening (Almajwal & Alam, 2020). From the results of discussions, eating disorders were expressed by almost all caregivers (mostly mothers of children with CP). The team provided information about the selection of types, ingredients, and also the consistency of foods that could be selected to improve the nutritional status of children with CP.

Another issue that emerged in the discussion was constipation which was commonly experienced by people with CP. Based on the source, the factors that influenced constipation were prolonged immobility, the absence of an upright posture to defecate, bone changes such as scoliosis, hypotonia, dietary factors such as insufficient fiber or fluid intake, and the use of drugs as an anticonvulsant (Almajwal & Alam, 2020). In addition to the consistency and type of food, the participants were taught about gentle manual physiological manipulation steps to help reduce constipation.

Epilepsy and seizure disorders were also associated with CP. Seizures were also a risk factor for epilepsy in children with CP and it could cause further mental retardation (Sadowska et al., 2020). In a study conducted by Pavone, the use of antiepileptic drugs was more frequent in the group of paralyzed children, but with targeted treatment, 54% achieved satisfactory seizure control. In some patients, the dose of the drug had to be adjusted and some patients could

gradually reduce the dose of treatment because it showed improvement (Oliva, et al., 2021). This study showed that with regular medication education, the use of seizure medication could provide benefits for CP children with seizures.

Before and after the implementation of the education session, participants answered eight yes or no questions as shown in Table 1. Medical problems found along with motoric disability in CP patients included malnutrition/gastrointestinal disorders and epilepsy (Sadowska et al., 2020). The questions were adjusted to the objective and essential things that were the problems or issues for CP. Based on the results of the evaluation using the questionnaire, it was found that there was an increase in the average correct answer answered by the participants, initially the average score was 59% and it increased to 92%.

The second stage of the evaluation was carried out through interviews and with Focus Group Discussion (FGD) on June 13, 2021. There were 10 participants who attended this second evaluation. This interview involved individuals with a small number of respondents to explore their perspective on a particular idea, program, or situation. In this evaluation, the volunteers provoke open questions according to the topics that have been given and the participants share their experiences of things that have been successfully practiced. In addition, questions that were asked by participants during the session would be asked again and become a benchmark for assessing whether there were changes in knowledge, attitudes, and behavior of Mitra Ananda members after counseling related to nutrition and seizures for children with Cerebral Palsy.

In this second evaluation, there was a significant change which was marked by changes in both the correct answers from the participants and the enthusiasm also the confidence shown by each question given by the university team based on the educational material they have followed for 1 month previously. Some things changes were quite good, such as how to handle

when a child was having a seizure. Before attending the class, information was obtained that when a child has a seizure, oil, and a spoon was inserted into the mouth and held the child in place so as not to make excessive movements. After attending the educational session, participants understood that it was enough to just avoid dangerous objects around them and it was better not to put hard objects but soft objects such as towels into their mouths. Another example, the caregiver did not know about the rectal toucher to make the defecation process not too difficult. After the counseling and practicing with a rectal toucher to stimulate bowel movements were successful, then the method was distributed in WhatsApp groups by one of Mitra Ananda's members. Participants can understand the symptoms of seizures, the nutrition that must be met, and what to do during a seizure and not do during a seizure. There were some things that still require the implementation process, such as there were still some who have difficulty eating, were hard to sleep at night, did not enjoy eating vegetables, and only want to drink milk.

From this evaluation, information was obtained that educational materials, summaries that have been made by service members, and independent notes made by caregivers were distributed to the Whatsapp group which were downloaded by members of Mitra Ananda who did not have the opportunity to attend because participants were also limited due to pandemic. In the FGD, it was also known that in the WhatsApp group discussions, the members asked questions that would be answered by the carrier present. Knowledge was successfully applied, actively communicated in the group, and imitated by other carriers. This showed the effect of multiplication in a wider scope. Telling each other from one member to another, the knowledge gained continues to spread.

Caregivers with Cerebral Palsy face a tough task that has both physical and emotional implications. The quality of life of Caregivers was correlated well with the motoric function of CP children. It was important not only for physical health but also psychological health of carriers of CP children, especially those with severe motor function (Yun, 2017). In order to improve the quality of life for people with Cerebral Palsy and caregivers, a support system was needed. A good spirit not getting caught up in a problem should be used as an example for others who feel the same fate and share the same fate so that, from a small group of empowered people, they can become agents of change for the surroundings and the wider community.

Table 1

Pre and Post-Test Questionnaire and the Results

No.	Questions	Percentage of correct answers	
		<i>Pre-test</i>	<i>Post-test</i>
1	Children with CP need high carbo.	0%	92.90%
2	The eating position was important	86%	100%
3	Food for CP has to be fluid and very soft (less fiber)	43%	78.60%
4	Children with CP do not need fiber	100%	100%
5	Seizure to CP always above 15 minutes	50%	92.90%
6	Continued blinking eyes were not an early sign of seizure	21%	100%
7	Bone development was not important for CP	100%	100%
8	Medication for seizures must be taken more than 4 times	50%	64.30%
Average		59%	92%

Conclusion

Health education has been carried out for the caregivers at Mitra Ananda so that they can manage nutrition and seizure management for children with CP. There was a positive impact on their knowledge, enthusiasm, and commitment to supporting each other. They supported each other by teaching the other members to share their experiences and new knowledge. This has an impact on caregivers who are more confident to take the right action with first aid when a child with CP has a seizure. The knowledge gained through education aims to empower caregivers to be more independent so that they can provide appropriate first aid for children with Cerebral Palsy, especially during this pandemic where children with special needs or in this case Cerebral Palsy have a higher risk of developing severe respiratory symptoms for that knowledge through education is needed to reduce mortality. The health education material was found appropriate as it was consulted and designed with the active participation of Mitra Ananda members. Confidence and understanding of a topic that was experienced and knows how to solve problems was the goal of creating a community that becomes a driving force to empower others through health education methods.

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