

FACTORS INFLUENCING PARTICIPATION IN ADAPTIVE *DIKIR BARAT* FOR CHILDREN WITH CEREBRAL PALSY: A CASE STUDY

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Children with cerebral palsy (CP) are most likely to encounter barriers that can prevent them from the opportunity for participation, namely in performing arts due to their limitation of posture and movement. Adaptive Dikir Barat (ADB) modifies its typical way to well suit the ability of children with CP while still maintaining the traditional musical elements and rhythm of the original Dikir Barat (DB). This study focuses on exploring the factors influencing participation of ADB for children with CP. The goal is to include and encourage them to participate in performing arts activity which is designed and adapted for their abilities. The positive result of this study from interviews conducted with seven parents of children with CP suggests that more research should be carried out to expand this activity in order for children with CP be given opportunity to perform more frequently.

Keywords: Children with cerebral palsy, adaptive *Dikir Barat*, performing arts

INTRODUCTION

Cerebral palsy (CP) is a disorder identified by cerebral functional impairment which often occurs in children during perinatal or postnatal periods; therefore, children with CP are characterised with motor disorders, cognitive deficits, visual and speech disorders (Duymaz, 2018). It is difficult for children with CP to fulfil their roles in society and thus affect their quality of life (Rosenbaum et al., 2007).

The potential of music as an activity has been widely recognized in different fields. Music can help connect motor and cognitive skills to facilitate learning and enhance emotional experiences. According to research done by Zhang et al. (2019), music has a certain effect for the treatment of paediatric CP, especially in improving children's gross and fine motor abilities, which has a certain clinical guiding significance for rehabilitation of children with CP.

Dikir Barat (DB) is a form of musical performing arts that is well known in Malaysia. It is performed in groups, usually consisting of 10–15 persons, and involves choral singing with musical instrument accompaniment (Bujang, 2005). One of the main reasons for DB to be chosen as an activity was due to its

aspect of cultural heritage which has received less attention these days due to globalization. Only just recently was awareness created among nations that the living cultural tradition should be cherished and preserved (Alivizatou, 2012; UNESCO, 2013).

Traditionally, in a typical setting of DB, performers usually sit cross-legged on the floor, while in ADB, children perform in the comfort of their own mobility aids, namely walking frames and wheelchairs. Prior to the opportunity performing ADB, they are often excluded from taking part, or they are the last person to be picked for any type of performance, and as a result, they will feel isolated and disengaged from their peers and community.

An ADB group for children with CP is made up of a few *tukang karut* (singer of the improvised lyrics), a group of about 13-17 chorus singers called *awok-awok* (musicians) who also play the tambourine, ring bell, maracas, and in our group, *pom-poms* were included to add joy to the performance.

Ambulatory ADB performers stood on walking frame with non-ambulatory performers in wheelchairs. They were positioned in close proximity beside each other, in one straight line on the stage as this orientation allowed each of the performers to be seen by the audience.

According to Sharifah Masturah (1999), traditionally, *tukang karut* (TK) initiates responses and challenges competing groups. *Karut* does not mean 'nonsense'. In the DB sense, it means '*spontaneous pantun*' (poetry) (Halim, 2007).

In ADB, a few TKs have been selected from children with less speech impairment and not categorized as non-verbal. Instead of impromptu, the TKs in ADB were given sets of lyrics where they have to memorize and sing according to their turn.

Awok-awok (AA) provides excitement through body movements, handclapping and singing to reinforce phrases sung by the *tukang karuts* (TKs). AA in ADB are also in charge to create excitement through body movement, and they do it while seated on their wheelchairs or standing with their walking frames.

Besides playing the instruments given, AAs also sing along to DB repetitive chorus together with the TKs. Uniquely, in ADB, *pom-poms* were added to add colour to the performance, as they are light in weight which is convenient for the children with CP to hang on to throughout the entire training and performance.

LITERATURE REVIEW

Mancini, Coster, Trombly, and Heeren (2000) stated that a critical gap exists on the factors that promote successful participation for children with CP. It is important to understand the factors that influence how and why children with

disabilities engage in activity; hence more participation can be encouraged and barriers for them to be active in their involvement in activities can be removed (Brown & Gordon, 1987; Law & Dunn, 1993; Law et al., 2000).

Through music, children with CP can improve in speech or language as singing along to songs creates a structure that can improve a child's fluency or rate of speech. Therefore, many health promotion programs have employed music as an activity to enhance the impact of health promotion (Davidson & Faulkner, 2010; Hampshire & Matthijsse, 2010; Rimer & Brewer, 2015; Ryerson, 2008).

In addition, effects of musical instrument training on brain structure and function have been especially investigated through imaging studies with trained musicians and non-musicians (Herholz & Zatorre, 2012). Playing a musical instrument demands the coordination of hand movements with integrated auditory, visual, and tactile feedback; hence it is a process that recruits multiple brain regions, which leads to the development and investigation of music-supported therapies, especially for rehabilitation with motor disorders resulting from brain damage (Alves-Pinto et al., 2016).

The rhythmic properties of music have also been explored to tackle impaired gait patterns through rhythmic auditory stimulation (Kim, Kwak, Park, 2011). Since playing a musical instrument requires coordinating hand/finger movements with sensory-auditory, visual, and somatosensory-information; it involves continuous forward and backward transmission of information between different brain areas and between central and peripheral motor structures (Herholz, et al., 2011).

DB is categorized as a traditional Malay traditional music and as art form that originated from the state of Kelantan (Azmi, 2006; Ghazali, 1995). However, while DB is believed to have originated from one of the states in Malaysia called Kelantan (Malm, 1974), some researchers argued that DB was spread from southern Thailand to Kelantan where it is not just localised but also spread to other parts of Malaysia (Ho, 2014; Osman, 1999). DB involves solo and choral singing, hand clapping, synchronised body and hand movements (sometimes even dance) accompanied by percussion instruments (Iskandar, 2014). Although there is no actual set size, it is typically performed by groups of ten to fifteen members (Patricia, 2003).

It is performed in a group with two leading singers in competitive environments. A group usually sits cross-legged on a platform, sometimes surrounded by the audience. Where the DB is performed competitively, the two competing groups will both be on the stage at the same time (Patricia, 2003). Traditionally, no musical instruments are used; hence the singing being accompanied by rhythmic clapping and energetic body movements instead. However, some groups do use a pair of frame drums or *rebana*, a gong and a pair of maracas for musical accompaniment (Aziz et al., 1994).

Competitions and performances were broadcasted on national TV and its songs played on the airwaves. From the *kampongs* of Kelantan, DB was pushed into the limelight and became known nationwide. According to Iskandar (2014), even schools and universities began to form their own DB groups. DB was usually performed during harvest seasons, weddings or festive celebrations, which according to research done on the history of DB, performers have always been all-male. However, in recent years, especially with groups based in urban areas, female performers are beginning to participate (Matusky & Tan, 2004).

Much research has been done to find the real history of DB in Malaysia. Back in the days, its popularity made it a suitable means of disseminating information and instilling values to the masses and thus promoted through the media as one of Malaysia's cultural heritage.

OBJECTIVES

This case study is conducted to explore factors influencing participation of Adaptive Dikir Barat (ADB) for children with cerebral palsy (CP).

METHODOLOGY

Research Design

The research used a case study with the purpose to allow the researcher to obtain and examine data in a context or phenomenon. According to Yin (2012), case study data is used to describe a case in-depth in real-life comprehensively. Hence, in this study, the factors influencing participation in ADB for children with CP were explored in-depth and descriptively.

Sample and Sampling Method

A sample of parents of children with CP was recruited during appointments at Alliance of Children with Cerebral Palsy, Malaysia (GAPS). The sample included 7 parents whose children with CP are with these following criteria - between 4 to 10 years old; motor impairment classified as levels II, III and IV according to the Gross Motor Function Classification System – Expanded and Revised (GMFCS- E & R); under the classification of diplegia and quadriplegia; have enough cognition to participate in group activities and understand the commands during ADB training; participants in the study group had to attend ADB training for at least three times and had prior participated in public performances. Parents whose children with CP above 10 years old, or with associated impairments namely, vision and hearing that would compromise participation in ADB were excluded.

Instruments

Interview was the main data collection technique for this case study. Interviews conducted were based on the list of questions prepared. Nevertheless, participants were allowed the freedom and given the rights to talk about their experience in which they felt mostly comfortable and secured. The researcher triangulated the interview data with field notes and document analysis to support and validate the findings in this study.

Validity and Reliability of Instruments

Validity and reliability of instruments process for this case study involved two panels; from Faculty of Education, National University of Malaysia (UKM) and Sultan Idris Education University (UPSI). The draft of the article namely title, abstract, objective, conceptual framework, participant sampling and instrument were emailed to the panels where the draft was reviewed and suggestions were provided to improve on the instruments proposed. Based on the feedback from both panels, the researcher made the revisions accordingly.

Procedure of the Study

The study was carried out between September 2019 and December 2019 around Kuala Lumpur and Selangor involving 7 study participants consisting of parents of children with CP. The purpose of conducting this study was to identify the factors influencing participation of ADB for their children with CP. Therefore, this study used a qualitative method, and data collection involved interviews with parents aged between 30 to 48 years old. Each participant involved in this study is known as participant 1 up to participant 7. Additionally, field notes and document analysis were added to support the data of the study.

All parents and caregivers signed an informed consent form for their participation in the study, and to maintain confidentiality, the researcher uses abbreviation, P1 to P7 referring to participant 1 to 7 involved in this study. ADB training was conducted by a trainer from PEDRA (Pelajar Drama Pusat Kebudayaan Universiti Malaya) over 24 months, with two-hour lesson per week, observing the following stages: group vocal warm-up, choreographic composition and improvisation, and relaxing. The activities were delivered in a location provided by Alliance of Children with Cerebral Palsy, Malaysia (GAPS).

Data Analysis

Interviews with the participants were recorded, transcribed, and from the transcript, factors influencing participation in ADB of children with CP are manifested. Field notes and document analysis were used to support the consistency of the findings in this study. Moreover, both field notes and data

analysis also provided additional perspectives that cannot be obtained solely through interviews. The results of the transcribed interviews have yielded five factors.

RESULTS

After interviews were conducted with the participants, 5 factors were obtained as follows;

- Child's Characteristics
- Parents' Support and Involvement
- Attitude and Interest
- Community and Cultural Relevance
- Resources

Factor 1: Child's Characteristics

Physical and cognitive condition of children with CP is one of the factors influencing their participation. Based on the questions posed to all participants, it is found that all stated that their child's characteristics i.e. GMFCS – E&R, influence their participation in ADB as the top priority. This can be shown through the statement stated by all participants such as: –

- P1: *"Because my child is in GMFCS Level II, he is able to do many things, including joining, training and performing for ADB."*
- P2: *"Her cognitive level shows that she understands instructions and able to follow the rhythm, so that is why she joins ADB."*
- P3: *"Yes, his level of understanding and abilities make me confident to sign him up for ADB."*
- P4: *"Of course the main factor is my child's characteristics; otherwise the activity will not be beneficial for him."*
- P5: *"My child joins ADB because I trust his cognitive level and physical abilities."*
- P6: *"My child's characteristics play an important role for my decision".*
- P7: *"Surely my child's condition and his capabilities motivate me to make him join ADB as an activity."*

Similarly, parents whose children are in GMFCS – E & R, Level III reported that their children's characteristics also influence their decisions. Through the field notes, it is also observed that children with CP who were involved in ADB are more independent, cognitively able to understand the instructions given

during training and able to express themselves clearly. These characteristics enable the participants to grasp the concept of ADB, consequently allowing great cooperation among them.

In addition, Figure 1 (with two performers in their ADB costumes) shows representation for CP classifications of ADB performers; a participant on a wheelchair – GMFCS – E & R Level III; while the other participant who is under the GMFCS – E & R Level II is able to stand on his own, nevertheless still depend on walking frame during performance of ADB.



Source: Researcher's collection

Figure 1. Child's characteristics in ADB

Factor 2: Parents' Involvement and Support

Parents play a central role in facilitating children with CP development, therefore, their parents' level of involvement and support play significant role in influencing factor of participation in ADB.

- P1: *"My child is more motivated to participate when I'm around, performing with him."*
- P2: *"If I didn't encourage her, she becomes shy and reluctant to join ADB."*
- P3: *"Yes, as parents I am always there during training, standing beside him."*
- P4: *"At first, I must hold his musical instruments to make him confident to perform for ADB, so I have to be there all the time to show my support."*
- P5: *"I always support his training sessions and I am also involved every time for my child."*

P6: *“My child feels more confident to join ADB when I tell him that I believe in his talent.”*

P7: *“I always make sure to be with my child all the time during training and performance so that his participation in ADB is more meaningful.”*

From the field notes, it is also observed that parents were with their children throughout the entire training as well as public performance. In addition to being supportive, it was also observed that parents were well-versed with the lyrics of the ADB song and contributed their voice and body movement while performing ADB with their children.

With reference to Figure 2 (i) and (ii), parents can be seen with their children, assisting and supporting throughout the entire training sessions as well as public performance – getting their costume, musical instruments ready as well as standing behind their children’s wheelchairs and frames.

Parent’s levels of support help to explain the relevance for their children’s participation. In addition, parents’ involvement and modeling of ADB has been identified as another factor connected to their children’s participation. From this study, it is found that parent’s support involvement in ADB has been shown to strongly influence their children’s achievement, engagement and motivation.



Source: Researcher’s collection

Figure 2 (i) & (ii). Parents’ involvement and support for ADB.

Factor 3: Attitude and Interest

Attitude and interest play an important part in determining the consistency and level of involvement in ADB for children with CP. It is found that attitude and interest toward ADB is another main factor influencing the participation of children with CP. This is stated in the statement by all participants such as:

P1: *“He loves music, and ADB becomes another form of music expression for him.”*

- P2: “My child is a music lover, and ADB is definitely one of it!”
- P3: “He gets excited when there’s ADB training.”
- P4: “My child always looks forward to ADB training and performance!”
- P5: “He loves ADB so much because he can be with his friends.”
- P6: “ADB always makes him smile. His interest in ADB keeps him in good mood.”
- P7: “His attitude towards ADB is always positive.”

The importance of attitude and interest in participation of ADB can be seen in the actions of children with CP who show positive attitudes. A positive attitude is indicated by ADB members who tend to be more diligent and cooperative during training so they may attain satisfying results and perform well.

Through the field notes, it is also observed that participants of ADB are enthusiastic and passionate on performing. This was manifested through their willingness to cooperate throughout the entire time and strong determination to get on with the training. Although some may have lost their focus during training, it was overcome when their names are being called by the trainer to get back on track.

In addition, based on Figure 3, it is seen that one of the participants (GMFCS – Level III) was independently holding on to his *kompang* (traditional musical instruments) despite his limited hand-functioning, which demonstrates his will power to be part of ADB performance. His commitment in playing his *kompang* signifies positive attitude and interest towards ADB.



Source: Researcher’s collection

Figure 3. Attitude and interest towards ADB

Factor 4: Community and Cultural Relevance

It is important to integrate culture in an adaptive activity. According to Brown et al. (2019), the implementation of strategies that foster culture sustaining in inclusive environments could be the support students with disabilities need to improve their skills, knowledge and awareness. It is found that community and cultural relevance is another factor influencing participation of children with CP in ADB. This can be shown through the statement stated by all participants such as:

- P1: *“Since DB is traditional music, I want him to learn through participating.”*
- P2: *“When I was in school, I also participated in DB, now that my child is with CP, I want her to also inherit the culture through ADB.”*
- P3: *“We are happy to be part of CP community needs which needs our support to promote ADB in performance.”*
- P4: *“As a Malay, I want to also expose my child to the culture through ADB.”*
- P5: *“It is important for my child to learn about ADB because it is part of our culture.”*
- P6: *“We must support the CP community through participation in ADB.”*
- P7: *“I want my child to know that our culture and traditional music are also fun and enjoyable, not just K-Pop!”*

From the field notes, it is also observed that participation in this activity give them the sense of togetherness, bonding and friendship throughout the entire time – before, during and after ADB performance. Similarly to a finding by Sharifah Masturah (1999) *“...each member (of a Dikir Barat group) is like a part of the human body. For the body to function well, each part has to serve well. The combination of ideas, the cooperation and enthusiasm among the performers are crucial for a successful DB performance.”*

Figure 4 communicates the overall picture on how cultural elements of ADB are being supported by the media when ADB performers, alongside their mothers were seen in this promotional poster for a program on Malaysia’s national television. This effort is significant to both introducing the talent of children with CP and raising awareness on ADB as relevant cultural performance to the community.



Source: Rangkaian Television Malaysia (RTM), Selamat Pagi Malaysia (Dec. 2019)

Figure 4. Community and cultural relevance ADB

Factor 5: Resources

In this study, resources factor refers to accessibility, transportation, and finances. Lack of facilities, programmes and accessibility can be factors or barriers toward participating (Murphy & Carbone, 2008; Rimmer et al., 2004); therefore, in order to remain consistent, it is found that resources play a role as another factor influencing participation in ADB. This can be shown through the statement stated by all participants such as:

- P1: *“The only location that offers ADB is in GAPS, and it is convenient for me.”*
- P2: *“My family and I are able to travel for ADB training and performances since we can still afford the cost.”*
- P3: *“It is no problem for my child to join because we can still manage to cover any cost for the training.”*
- P4: *“We have been with GAPS for so long and it is convenient for us to join any activity organised, including ADB.”*
- P5: *“I am okay with the location, trainer and other costs regarding my child’s ADB training or performances.”*

P6: *“It’s good that GAPS organised this activity, and allows us to join.”*

P7: *“My child finds it easy to participate and I find it convenient with all resources available.”*

Organisations serving for the disabled should be barrier free for easy access and to increase the rate of participation (Mohamed & Husin, 2019). From the field notes, it is also observed that participants of this activity, given the circumstances, were able to function accordingly. Furthermore, with the organiser of ADB prioritising in ensuring convenience to the participants, the researcher was able to indicate that the resources mentioned in this study, namely facilities and location were favourable to the participants and their parents.



Source: Researcher’s collection

Figure 5 (i) & (ii). Resources influencing factors in ADB

Based on Figure 5 (i) and (ii), evidence on the ample space provided during training and facility such as ramp, can be seen. These amenities make it suitable for the participants to move around with their wheelchairs and walking frames.

This implies a greater commitment is needed from all involved, namely organization, trainer, location, and parents to ensure participants, namely parents of children with disabilities are able to attain and manage their resources well, hence enabling them to encourage their children to participate in more beneficial activities.

DISCUSSION

With reference to Maciver, Rutherford, Kramer et al. (2019), only Imms et al. (2017) has conducted research that integrates various factors which concluded that participation phenomenon is essentially dichotomous, which requires children to be present and to engage in the experience. Children's knowledge and understanding of roles are also factors which influenced their participation (Maciver et al, 2019).

Additionally, a study on factors influencing physical activity was conducted by King, Law et al. (2003) to determine the nature of important factors affecting participation for children with disabilities. This study provides important information for the development of a comprehensive model of the environmental, family, and child determinants of the participation of children with disabilities.

According to Rosenberg, Ratzon et al. (2013), no single factor fully explains variance in participation, while Imms et al. (2017) stated that previous research provides indications of which features of the child significantly affect the participation of students with disabilities, which include focus on psychosocial factors for participation, such as preferences.

According to Arakelyan, Maciver et al. (2019), previous studies have examined personal and environmental factors that affect participation of children with disabilities, where the most commonly identified factors were child age, sex, skills and functional abilities, preferences and enjoyment, parental values and preferences, supports and acceptance from others, and accessibility of physical environment.

A study by Sivaratnam et al. (2020) states that a child's confidence in their skill level was perceived to be a key factor to participation. Motor skills and social skills of children are considered as the most important factors (Bult et al., 2013), while Majnemer et al. (2009) concluded that age was an effective factor for participation.

With reference to Trost and Loprinzi (2011), parental support, particularly positive encouragement and interpersonal actions are critically important towards children's participation. Horn and Horn (2007) explain that parents' support towards their children such as modeling, providing opportunities and emotional support influence the child's behaviour. Therefore, the need to focus on family unit and better understand family factors contributing to children's participation is important (Anaby, Hand, Bradley, et al., 2013).

Children's attitude and interest relating to inclusion were frequently discussed as influencing whether parents enrolled their child in ADB. With reference to Kind et al. (2007), attitude is a reaction to a situation that is positive or negative, or also defined as individual beliefs and feelings towards a situation or an object. According to Vygotsky (1978) development of an individual is connected with the social and cultural activities in which he or she participates together with other people. Additionally, Littleton and Miell (2004), state that

values namely collaboration, shared goals, engagement, involvement, interdependence and commitment to one another, are examples connected to the characteristics of participation in community.

Albrecht, Skiba et al. (2012) argued that special education programs need to be culturally relevant and that this is the means by which these students' behavioural outcomes are improved and the inequities that exist for them in schools can be reduced. Additionally, according to Racz, Putnick et al. (2017), much of the study on behaviour of children with special needs recommends the management of behaviours in more productive and culturally sensitive ways. On the other hand, a study by Sivaratnam, Howells et al. (2020) stated that availability of family resources, namely time and financial limitations were commonly identified as factors influencing participation for children with CP.

LIMITATIONS AND FUTURE DIRECTIONS

Further studies can explore the benefits of ADB by interviewing the children with CP and their parents to reflect on their participation. Apart from small sample size, it was not relatively diverse in terms of race, ethnicity and family background. Further larger studies are needed to explore the benefits of ADB as an activity for children with CP.

CONCLUSION

ADB was found to create a culture of inclusion among children with CP, which may in turn improve their quality of life. Movement, instruments and music therapy from ADB have been found to increase social interaction, decrease anxiety, enhance communication, and stimulate physical activity within the population of cerebral palsy – especially among the wheelchair bound. From the case study, all parents of ADB performers understood the importance of this activity and encouraged their children to participate in ADB training and performance. Parents also delivered great team work with the trainer and organiser of ADB. Factors influencing their children's participation as analyzed, demonstrates their willingness and cooperation towards the activity. Regardless of their children's level of participation in the performance, parents were able to give good cooperation during show time.

Music already plays a central role in the management of children with CP, where it promotes personal and emotional enrichment, socializing, and relaxation. It was found that parents of ADB performers agreed that the activity is highly beneficial and useful to enhance their children's quality of life through participation, performing in public as well as the skills involved towards achieving the aim. Thus, activity such as ADB can be used as creative activity

for children with CP. However, more research is needed to validate, support, and guide the optimal use of movement and musical instrument used in ADB in the learning of sensorimotor abilities in children with CP.

Parents, service providers, and policy makers need to understand which intrapersonal, interpersonal, and environmental factors are the most important determinants of children's participation, and in addition, how these factors operate together to limit or enhance participation. It is also important to know whether these factors change as children develop. Without knowing the factors, it is difficult to plan activities which can enhance children's participation or to design effective policies and programs for children with CP.

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