

Conservative Management Techniques for Ideal Grooming and Upbringing of Downs Syndrome Children

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ABSTRACT

Background: Down syndrome are slow learners having mild to moderate intellectual disability with co-morbidities, we need to pay special attention on conservative management techniques like early intervention programs, speech therapies, physiotherapies, exercises, sports, schooling and education etc. to make these children intellectual compatible for a normal life.

Aim: To identify the conservative management techniques for improving the quality of life for down syndromes.

Methodology: A descriptive cross-sectional survey (designed after literature search) was conducted from the parents of Down Syndromes at special children's schools in Islamabad and Rawalpindi according to inclusion criteria i.e., school going down syndromes and residents of Islamabad and Rawalpindi, in an interactive counselling session conducted by authors in collaboration with pediatrician, keeping the questionnaire anonymous.

Results: For the management of Down Syndromes, out of 44 parents, 36(81.8%) agreed on home based teaching, 34(77.3%) agreed on exercise, gym and sports for down syndromes. Around 38(86.4%) agreed on speech therapy and social interactions, 31(70.5%) parents agreed on controlled and healthy diet and 34(77.3%) parents said brain storming and learning new things should be in practice for down syndromes.

Conclusion: Down syndrome is a complex condition requiring a multi-disciplinary team of professionals to manage the myriad of problems faced by the patients. Aside from these, a vital role is played by parents, teachers & the community itself in taking care of these special individuals. Also, Down syndrome is characterized by learning disabilities as its hallmark feature but their learning abilities can be improved through certain conservative management techniques.

Keywords: Down Syndrome, School, Exercise

INTRODUCTION

Down syndrome (DS) is the commonest chromosomal disorder recognized by subnormal intellect, delayed developmental milestones and typical physical characteristics¹. Incidence of this disorder is 1/1000 live births. There is an additional genetic material present at 21st pair of chromosomes. Physical characteristics of this disease include simian crease, reduced muscle tone, oblique eyes, flat nose and small fingers².

Children with DS are more prone to certain diseases like cardiac defects, blood cancers and immune related diseases³. Family members of children with this disorder encounter different challenges with regard to physical and mental well-being of these individuals⁴. Quality of life of people with this condition has improved significantly in the last five decades and their life span has increased mainly due to early diagnostic facilities and improvement in management strategies. DS management involves many disciplines like physical therapy, treatment of medical issues, psychological support and addressing social and cultural issues related to this disease. Physiotherapy, if initiated earlier in life can help attain motor milestones like ability to walk etc. and this will avoid complications in later life⁵.

Delayed speech and other language related issues are common in children with DS⁶. Speech therapy proves to be a beneficial modality for addressing speech related issues in individuals with this disorder⁷. Adopting a life style with regular physical activity has proved to be worthy in these individuals⁸. Adequate teaching techniques along with correct teaching tools can help in enhancing the learning skills of patients with DS⁹. The role of parents is critical in educating the individuals with this disease. Parents can support their children with DS to enhance their learning skills and educational capabilities so they can become a useful member of the community¹⁰.

The objective of the study was to identify the conservative management techniques for improving the quality of life for down syndromes.

METHODOLOGY

This is a descriptive cross-sectional study. It was designed after the systematic literature review. The systematic literature review was done using online databases such as pub-med, google scholar, and the library of Al-Nafees Medical College. An awareness workshop was conducted to survey conservative management techniques from parents of DS at Special Children Bahria College Islamabad and Sedum Special Children School Rawalpindi. The workshop was an interactive counseling session. The authors conducted the counseling session in collaboration with the pediatrician. Informed verbal and written consent were taken prior to the session from the institutes and the parents. The questionnaire was kept anonymous.

The awareness workshop consisted of two sessions. During the first session, a survey questionnaire was handed over to the participants to gather the required information for our descriptive cross-sectional study. The questionnaire's first part was based on demographic questions. In contrast, the second part of the questionnaire consisted of series of questions regarding management of DS children in different given scenarios. The second part of the session focused on educating the parents and helping them understand how to manage their DS children in different daily life scenarios.

Our sample size comprised of 44 participants, the inclusion criteria were parents of school-going down syndromes, residing in Islamabad and Rawalpindi. Our study included students with DS aged 5 to 32 years of age. The diagnosis was reconfirmed through school documents, along with confirmation by the doctor interviewing their parents. Data analysis was done by SPSS v25 for statistical analysis

Received on 24-10-2021

Accepted on 14-04-2022

RESULTS

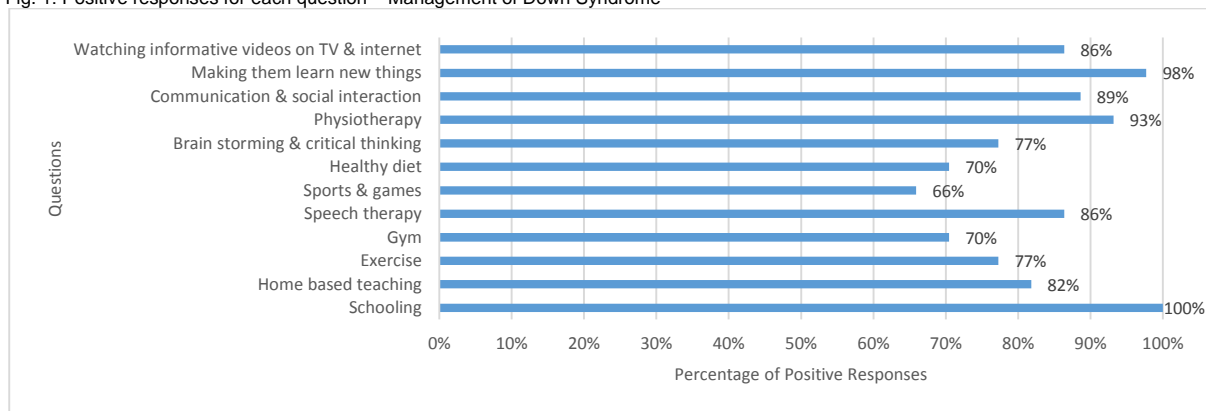
A total of 44 individuals with DS were included in this study, of which 23(52.3%) were male & 21 were female (47.7%). The ages of the individuals ranged from 5 to 32 years, with a mean age of 15.7 ± 7.6 years. All the parents unanimously agreed that schooling is beneficial for management of DS children. 36(81.8%) parents advocated the use of home based schooling for education of children with DS. Physiotherapy was considered to be a valuable aspect on management of DS children by 93.2% of parents (n=41), whereas speech therapy was considered a vital part of management by 38(86.4%) parents.

Regarding the importance of activities that promoted physical health, 34 parents (77.3%) considered exercise to be useful,

whereas 31 parents (70.5%) believed that going to the gym & a healthy diet was good for their children. 29 parents (65.9%) considered sports & games to be an important part of management.

In regards to activities contributing to acquiring new information & enhancing mental functions, 43 parents (97.7%) believed that DS individuals should be made to learn new things. 38(86.4%) parents agreed that the acquisition of knowledge could be effectively done by watching informative videos on TV & internet, while 34(77.3%) believed brainstorming & critical thinking were important for the development of mental faculties. 39(88.6%) parents also considered social interaction to be an integral part of management of DS children.

Fig. 1: Positive responses for each question – Management of Down Syndrome



DISCUSSION

DS patient suffer from a host of problems, including sub-normal intellect, cardiac defects, poor motor skills & poor speech production. In this study, however, we focused only on issues pertaining to the development of physical & mental health.

In our study, all the parents endorsed schooling for management of DS children. In a study conducted in India, by John et al¹¹, 95% caretakers believed that their children should be sent to school. Of these, 55% caretakers preferred regular schools, 35% special school, while 5% opted for integrated schools. Similarly, in a study conducted in Jeddah by Alhaddad et al¹², 89% caretakers believed their children should attend mainstream schools. Bantero et al¹³ determined that 99.6% of Spanish children with disabilities, including DS, studied in regular school. However, the parents & teachers leaned towards special education specialists for children with special education needs. Ranzato et al¹⁴ also noted that 77% of DS children in London attended mainstream schools.

It is worth mentioning that at Special Children Bahria College & Sedum Special Children School, where the study was carried out, senior students are encouraged to work as facilitators to help teach the junior students at their own schools. The schools also work really hard in teaching and polishing practical skills, so that their students can become more independent. This serves to create an environment within the school where the children & teachers are all accepted and valued members. In addition, this creates an environment where all the children can thrive & reach their full potential, while at the same time, serving the community.

While 81.8% of parents in our study agreed that home schooling is a crucial part of educating DS children, studies have determined problems associated with this process. Westerveld et al¹⁴ argued that while home literacy was a very valuable resource for DS education, children experienced poor attention & required shorter teaching sessions. Ranzato et al¹⁵ also demonstrated that parents had difficulty in teaching due to lack of attention & motivation in their children. Nayir et al¹⁶ showed that even in children without DS, inattention was a prominent concern, and that 58.9% parents experienced difficulty in maintaining their children's attention.

Physiotherapy is an important aspect in conservative management of Down syndrome. Studies highlighted delayed motor functions including independent standing and walking along with balance and postural maintenance¹⁷. However, early intervention by various physiotherapy techniques like treadmill training, massage therapy along with task specific training sessions and balance and posture training showed promising results in acquiring better and early motor function in children with DS^{17,18}. In a study conducted in Pakistan by Afzal et al, it was asserted that physiotherapy significantly improved the quality of life in Down children¹⁹. Similarly, Gonzales et al, illustrated the benefit of physiotherapy in improving muscle strength & cardiopulmonary capacity. It was also stated that physiotherapy helped in weight control, which was crucial as obesity & overweight were prevalent in DS⁵.

DS children experience delay in development of language skills as well as poor speech production due to speech motor control problems & hypotonia. Speech therapy is of critical importance to allow these children to communicate effectively. However, in a survey conducted in Canada, 60% of children with disabilities did not receive speech language services⁷. However, awareness for requirement for speech therapy is encouraging. In India, 79% parents were aware of the availability of speech therapy compared to 86.4% in our study¹¹.

Muscle hypotonia, joint hypermobility & laxity of ligaments are features of DS leading to gross motor deficits & delays in motor development. Consequently, DS children are less able to engage in physical activity, thereby increasing the risk of sedentary lifestyle & cardiometabolic health²⁰. Research demonstrate the benefits of physical activity in improving fitness, aerobic capacity & lower limb strength²¹. Ruiz-Gonzales et al also described an improvement of cardiopulmonary capacity, muscle strength & weight control with exercise⁵. Mas et al stated that games contribute to the child's physical, psychological & social health²². In our study, only 65.9% parents appreciated the importance of sports & games for their children. This implies a need to increase awareness & promote inclusion of DS children in sports activities.

Communication & social skills are the mainstay for becoming a part of a community. This provides a challenge for DS not only in regard to their speech difficulties but also in regards to a community

where they may not be accepted. As shown by John et al, 24% of children with DS are subjected to staring & harsh words and 14% of parent's felts like crying¹¹. Development of social skills & communication is primarily done by parents when the child is young & then by the community as a whole as the child matures. In a case study by Cartez Preza, it was highlighted that parents who do not support their children to develop speech have a poor vocabulary. In an interview with a teacher, it was discussed that parent form the most part of a child's education²³. Educational activities such as shared book reading also serve to promote social interactions & communication, especially in a school setting¹⁴. Robles-Bello et al concluded in their study that social skills training program improved communications & the different emotions that accompany them, thus enabling the children to become an effective part of society²⁴.

Brainstorming activities, critical thinking & exploring new ideas are all components of development of mental faculties in children. In the current era, parents are greatly helped by digital technology, allowing them to teach their children in an engaging manner. Ranzato et al determined that 91% of children had access to technology on a daily basis¹⁵. This correlates closely with our study in which 86.4% parents approved the use of technology for educating their children. Al Mammary et al talked highlighted Assistive technology (AT) & Information & Communication Technology (ICT) as effective tools in improving & developing social skills as well as academic achievement. AT & ICT also allowed children to communicate with others & thus develop their social skills²⁵. However, it must be noted that technology is not free of problems. Gonzales et al identified various difficulties faced by Down children when using computers such as lack of patience, frustration when too many windows open & low error tolerance. Gonzales advocated the use of gamification to maintain children attention & to make the process of learning an engaging & entertaining experience. In this regard, it was noted that while 40% users had negative emotions at the beginning of the session, only 10% experienced negative emotions in the final session²⁶. Thus, it is apparent that technology has an essential role in educating children with DS.

CONCLUSION

DS is a complex condition requiring a multi-disciplinary team of professionals to manage the myriad of problems faced by the patients. Aside from these, a vital role is played by parents, teachers & the community itself in taking care of these special individuals. Also, DS is characterized by learning disabilities as its hallmark feature but their learning abilities can be improved through certain conservative management techniques. If these techniques are adopted, individuals with DS can learn certain skills and become a useful member of the society

Acknowledgement: We are grateful to the mentors of Al-Nafees Medical College and Hospital for guiding us throughout this research's conduct, also thankful to Special Children Bahria College, Islamabad and Sedum Special children school, Rawalpindi for allowing us to conduct the awareness workshop and to collect the data. And special thanks to Brig. Dr. Muhammad Asghar Nasim, afwc, SI(M), SI(E), Mrs. Naeema Asghar and Mr. Soban Khan for being the guest speakers at the awareness workshops and helping in data collection.

Ethical considerations: Informed consent from both the institutions; Special Children Bahria College, Islamabad and Sedum Special children school, Rawalpindi, was taken to conduct awareness workshops for the parents of children with DS, along with which pre-workshop and post-workshop questionnaires were filled, after taking written informed consent from the parents to participate in this research willingly. The questionnaires were filled at the institutions from the parents, in the presence of their special children and their teachers. The identities of the parents will be kept anonymous and the confidentiality will be maintained. There was no breach of professional ethics at all.

Disclosure statement: The authors report no conflicts of interest. The authors, alone are responsible for the content and writing of this article. No grants were taken for the conduction of this research.

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