ATTITUDES ANALYSES OF MOBILITY DISORDERS ADOLESCENTS' PARENTS IN REGARDS OF IMPROVEMENT SOCIAL AND HOUSEHOLD SKILLS

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ABSTRACT

The purpose of this study is to analyse the attitudes of parents of adolescents with mobility disorders regarding the need to improve their children's social and household skills.

The methodology of data collection, processing and analysis of the research is based on the approach of quantitative methods, which allows combining the collection of quantitative data, using quantitative methods, later having the opportunity to conclude the data obtained through certain numerical patterns. The specially designed questionnaire was administered to 125 parents of adolescents with mobility disorders.

The survey showed that the vast majority of parents consider their children's independent life as a priority. The need to teach their children social and household skills such as shopping, cooking, cleaning kitchen utensils and the area, helping with household chores is also mentioned as quite important.

At the same time, the insufficient awareness of parents about the idea of living an independent life, the inconsistency of adolescents' ability to carry out household activities, the inconsistency between their subjective perceptions, as well as the overprotection possibility of one of the traditional Armenian cultural features should be mentioned too.

Keywords: adolescents with mobility disorders, mobility disorders, social skills, household skills, parents, caregivers, independent life.

INTRODUCTION

There are a number of social factors in the life of a disabled adolescent that is directly related to a person's ability to live in society, and to feel like a full person in society. These factors include education, family life, interpersonal relationships, housing conditions, health status, health and social protection system, opportunities provided by the state in the country, etc.

In recent years, approaches to the rehabilitation process have shifted from strict medical to social approaches, where clients' attitudes, views, and experiences have become more powerful. The client's participation is a central part of Occupational therapy and is reflected in the professional ethical principles established by the American Association of Occupational Therapists (AOTA, 2005). It clearly states that Occupational therapists interact with both clients and their families throughout the assessment, intervention planning, and intervention (Min, Ashe, Estes, Foster & Slater, 2010).

Social and household skills interventions for adolescents with mobility disorders are often delivered in intervention correspondences, containing a blend of numerous intervention structures considered to be operative in improving specific patterns. The presented below literature review revealed the state of adolescents with mobility disorders following Occupational therapy intervention features, which are commonly included in the social and household skill intervention process.

LITERATURE REVIEW

According to the classification proposed by the Soviet-era psychologist Elkonin, two periods of adolescence are distinguished: junior adolescence (12-14 years) and senior adolescence (early youth) 15-17 years of age. Adolescent development is complex; involving the interaction between fundamental biological and cognitive developmental processes, and the unique environment inhabited by the adolescent (Bell, 2016).

Entering puberty heralds the physical changes of adolescence: a growth spurt and sexual maturation. Professionals who work with adolescents need to know what is normative and what represents early or late physical development to help prepare the adolescent for the myriad changes that take place during this time of life (APA, 2002; Coleman & Hendry, 1999).

Mobility disorders affect the lives of adolescence at different levels, and the need for support, care and treatment varies between individual children and adolescents during their development and throughout their lives. The condition of each particular case has different direct effects on the development (Jemtå, 2008). Medical treatment including surgery, single or multiple hospital admissions, physiotherapy, occupational therapy, speech therapy, trying out orthopaedic and technical aids are examples of ordinary experiences for many adolescents with mobility disorders. Children and adolescents with impaired mobility have to manage varying degrees of physical dependence on parents, siblings, friends, personal assistants, and other people in their social life (Jemtå, 2008) as well as while performing different household activities.

According to the World Health Organization (WHO), about 70% of premature deaths in adults are due to adolescent behaviour (WHO, 2005; WHO, 2016). In the face of such alarming data, attitudes and conceptual approaches to adolescent health issues have begun to change in many countries. However, health care systems are not always able to respond to the needs of adolescents promptly. Many adolescents do not have the experience and practice of seeking medical help, which is largely due to problems in the health sector (Melkumova, Movsesyan, Sargsyan & Babloyan, 2019).

Conferring to data provided by WHO, about one-third of teens today have a chronic illness or condition. It was traditionally accepted that the beginning of adolescence is puberty, and the end is related to the ability to get a profession, work, get married, have children. Still, it is obvious that in the developing world today, both education lasts longer and the age of marriage and having the first child has increased significantly (WHO, 2016).

Access to the physical environment, public transport, information, communication, including information technology, buildings, and other services is essential to enable people with disabilities to live independently and participate in public life. At the same time attitude towards these persons as well as cultural peculiarities within the families seems to be vital as well. However, society often limits other opportunities for education, profession, work of the disabled, as the disabled mainly need treatment, care and attention. The life of a person with a disability depends on the opinions of others and attitude, which leads to his/her social isolation and hinders his/her full participation in public life. In conclusion, it should be noted that at present, there is a misconception in society about the problem of disability. Some people think of a person with a disability as just a person in a wheelchair, a walker user, or a bedridden person. Meanwhile, there are different manifestations of disability, which are united in one common term. Unfortunately, society's benevolence towards the disabled is often limited to the word "disability". At the same time, adolescence is not only a time of risks but also a time of opportunity. Adolescence is one of the most important stages of a person's life cycle, and adolescents are at a unique “crossroads of health”. In prenatal, early childhood and school-age, various biological and social factors, diseases affect and predetermine the state of health in adolescence (Melkumova, Movsesyan, Sargsyan & Babloyan, 2019).

In the work “Raising a Disabled Child”, the authors emphasize the importance of family involvement as a suggestion to parents of children with disabilities. The process of caring for a child with a disability poses a number of challenges for parents, such as additional financial difficulties to improve the child's health, ways to address problematic behavioral manifestations, overcoming societal stereotypes about disability, and more (Ha, Greenberg & Seltzer, 2011). Psychologists, Occupational therapists and specialists from the related fields have always the prioritized role of parents and used the participation of parents and family members in the planning of their children's intervention and further decision-making process (Hanna & Rodger, 2002). Guided by the ideology of the client-centred approach, within the frame of current research, it becomes possible to consider and analyze the attitudes of parents of adolescents with mobility disorders and views on their children's vision for the future, as well as the need to improve their social and household skills.

Depending on the type and severity of the disability, there are certain problems in the field of self-care and productivity, which act as the cause of very serious complications. In this situation, the person feels dependent and helpless. In this case, while talking about persons with mobility disorders, it is very important to ensure the adjustment process, as maximum conditions must be created for the person with a disability to be independent. It should be noted that in today's reality, the physical environment is still far from being accessible to people with disabilities, for providing full opportunities for a free life, and, thus, depending on the type of disability, in some situations, people with disabilities may need constant help. A person with a disability needs to be able to be independent, to have adapted and adjusted environment according to his/her needs, as well as to have regulated daily life and free performance of the activities of daily living.

Research on well-being among children and adolescents with mobility impairment embraces a variety of aspects, such as life satisfaction, and predominantly quality of life, independent living and health-related quality of life. Livingston, Rosenbaum, Russell, and Palisano (2007) reviewed research on the quality of life and health-related quality of life in adolescents with cerebral palsy and found lower well-being among those with cerebral palsy compared to normative data (Livingston, Rosenbaum, Russell & Palisano, 2007; Jemtå, 2008).

Using an age-related disease-specific instrument, where the adolescents self-reported, Schoenmakers et al. investigated the self-reported health-related quality of life and functional abilities in children and adolescents with spina bifida. These authors found being independent in mobility more important for the quality of life than being independent in self-care or being wheelchair-dependent (Schoenmakers, Uiterwaal, Gulmans, Gooskens & Helders, 2005). Other studies have demonstrated a significantly lower self-reported quality of life for children with cerebral palsy experiencing pain (Russo, Miller, Haan, Cameron & Crotty, 2008; Dickinson, et. al, 2007). Still, despite the fact of using different data sources, reviewed literature indicates that studies on well-being that are based on interviews with adolescents and their parents are rare.

METHODOLOGY

Data collection and participants

Participants of the study are the parents of adolescents living in different regions in Armenia (Yerevan, Shirak, Lori). 125 participants took part in the face to face and online surveys (Table 1). Taking into account the fact that there is no research ethics committee in the Republic of Armenia, gaining an official ethical license for the research was not possible.

All research participants were given the written information on the research aim, their rights, and the ethical obligations of the researcher. Also, informed consent was introduced to the participants. The names of the participants were kept anonymous and not used in the study.

A quantitative method of data collection and analysis was chosen in the current research as it provides complex textual descriptions of how people experience a given research issue. It provides information about the "human" side of an issue - that is, the often contradictory behaviours, beliefs, opinions, emotions, and relationships of individuals (Mack, 2005).

The questionnaire consists of 5 close questions, and parents need to select the answer they find more appropriate for them.

As a result, the answers received from the questionnaire were entered into the relevant software database (Microsoft Excel), where the collected data were analyzed and the digital percentage points were presented.

Table 1.

Demographic data of participants.

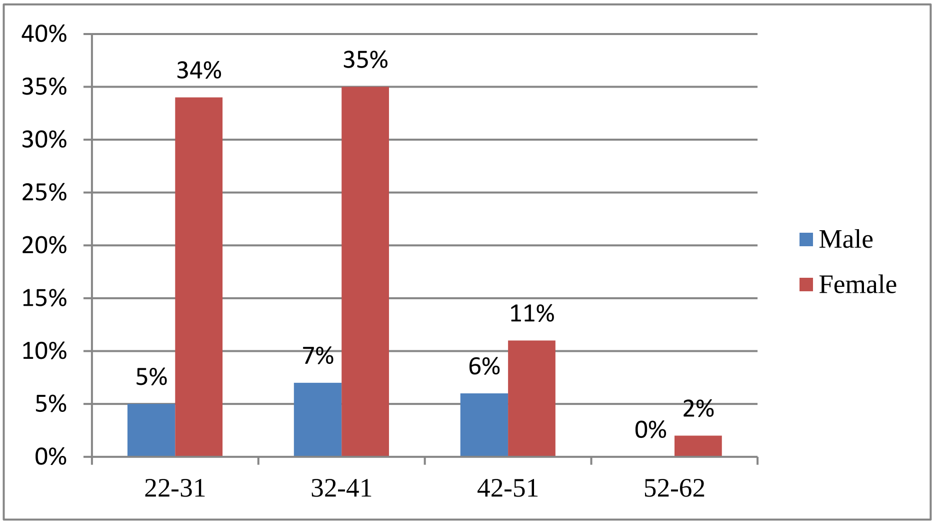
Region	**Sex**				**Age**							
	Female		Male		22-31		32-41		42-51		52-62	
	n	%	n	%	n	%	n	%	n	%	n	%
Yerevan	15	12	1	1	4	3	8	6	4	3	-	-
Lori	68	54	15	12	34	27	34	27	13	10	1	1
Shirak	19	15	7	6	10	8	10	8	5	4	1	1
Total	102	82	23	18	48	39	52	41	22	17	2	2

RESULTS

The gender and age composition of the parents or guardians who participated in the study are presented in Figure 1 below. The analysis of the obtained data showed that the age threshold of 125 parents participating in the research varies from 22 to 62 years old. The diagram below shows that the vast majority of parents or guardians are female. This may be due to the fact that in the Armenian society as an emphasized cultural feature it is accepted that the role of daily care and upbringing of children is assumed by the mother of the family and the father acts as the financial stability and welfare ensuring of the family.

Figure 1.

Gender and age group of the parents' participants of the study.

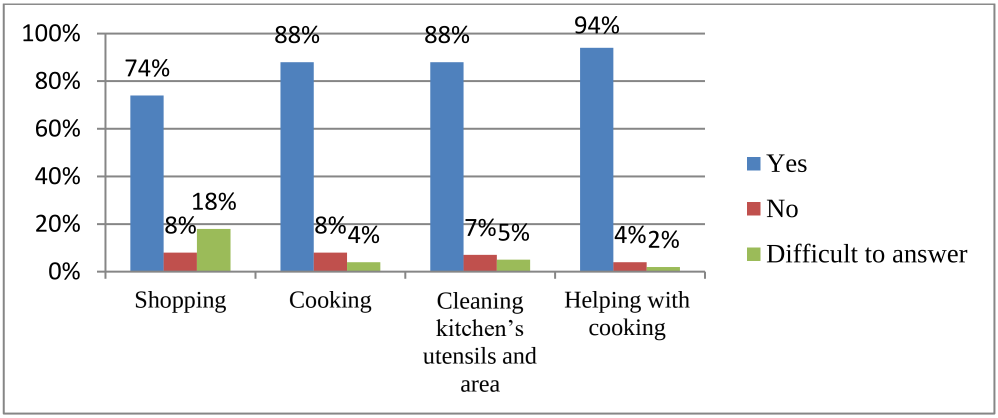


It should be added that the dominant part 62% of responders have secondary education, 14% vocational and only 24% have higher education. Referring to the index of higher education results the above-mentioned 24% by regions was distributed as follows: Yerevan - 10%, Lori - 9%, Shirak - 6%. For centuries, the prevailing view is that family is the main traditional institution of the child's upbringing, his physical, mental, intellectual and moral development. Undoubtedly, the level of parent's education plays a decisive role in the child's socialization, versatile development, pedagogical and rehabilitation impact of early measures, as well as in the fight against stereotypes related to disability.

To the question, "Do you support the idea that when your child becomes an adult, will be able to live an independent life with at least under your care?" the majority of parents (all 100%) gave a positive answer. At first glance, this indicator clearly reflects parents' position and vision for the future of their children as independent living people. However, the following questions which are presented in Figure 2, reflect the position of parents regarding adolescents with disabilities, social life skills, in particular in the implementation of the most important functions of everyday life and about the importance of availability, despite the fact that directly originates from the previous question and are considered its logical continuation, the indicators of the received answers are slightly contradictory and different. If the previous question, that's "Do you support the idea that when your child becomes an adult, will be able to live an independent life with at least under your care?" the majority gave a positive answer, then to the next more detailed question "Do you consider it necessary to teach all the skills that will help your child to be more independent in such activities as shopping?" the vast majority - 74% of parents gave a positive answer, while 18% found it difficult to answer and only 8% answered that they do not consider it important. Let's add that according to the WHO ICF classification characteristics, shopping includes the following interrelated functions such as choosing and purchasing necessary items for everyday life, such as food, clothing, household items, etc. This raises a controversial question and may conclude that 26% of respondents do not have a clear idea about the importance of household activities, such as shopping, or based on their children's functional abilities never imagined to their children as a direct independent participant in the above action.

A similar picture was obtained during the analysis of the next question answers: "Do you consider it necessary to teach all skills that will help your child to be more independent in such activities such as cooking?" which includes planning simple or compound meals, organizing, preparing and serving them, such as compiling a menu, choosing edible food and drink, combining food components during cooking, cooking with electricity, and making cold dishes and drinks, and also how to serve food, including simple, compound meals, 88% of respondents gave a positive answer, 8% answered that they do not consider it important and only 4% found it difficult to answer. In this case, 12%, which does not match the views expressed by the parents or guardians, and the latter consider their adolescent's people, who can live out of their immediate care. And again it is possible to conclude that this time it is based on the discrepancy between the adolescents' ability to be independent during household activities, and the subjective perceptions of the parents, or the possibility of one of the traditional Armenian cultural features, the overprotection.

Figure 2.
The importance of developed skills for independent living.



Referring to the next question, that is, "Do you consider it necessary to teach all skills that will help your child to be more independent in such activities such as, cleaning kitchen's utensils and area?" obtained the following, 88% of respondents believe that these skills will encourage their children to participate in household life, while 7% do not consider it important, only 5% could not answer clearly. Let's add that cleaning the kitchen area and dishes include such functions as, cleaning up after cooking, such as dishes, pans, small boilers, and washing kitchen utensils, cleaning the tables and floors around the kitchen area and etc. It is noteworthy that 7% of the respondents who think that involvement in these above-mentioned activities is not so important for leading an independent life, were male parents or guardians. This also may have been conditioned by cultural specificity. According to that, the main role of household life in Armenian families belongs to females.

And to the last question "Do you consider it necessary to teach all the skills that will help your child to be more independent in such activities as helping with housework?" which includes working with other people by planning, organizing, and managing household chores, when responsible is another person. The majority 94% of parents gave a positive reply, adding that if their children are not able to perform above-mentioned activities on their own, then at least will have an opportunity to participate in household activities. 2% of the respondents found it difficult to answer, and 4% mentioned that it is not important for their teenagers. Comparing to the other questions above, it must be noted that in this case was received the highest number of positive answers. It is considered necessary to mention this once that adolescents play a secondary role in performing these activities by receiving specific instructions from other participants and are not the main responsible. Analyzing the answers and comments of the respondents it might be concluded that the majority of parents consider important the idea that their adolescence, if not fully, can at least partially participate in household activities.

DISCUSSION

Thus, according to the answers of the parents, it becomes possible to conclude that the vast majority of the latter consider important the vision that their children may live an independent life. The need to teach social skills to their children such as shopping, cooking, cleaning kitchen’s utensils and areas, and helping with housework has also been highlighted.

Of course, these indicators are quite gratifying, as they prove gradual decline of once-dominant stereotypes in Armenian society and among parents of disabled children and teenagers, when people with disabilities were seen as a vulnerable minority and were based on stereotypes that caused compassion, fear, dependence from others, disability, and desire always to be supported. All this is quite similar to the result introduced by Ha, Greenberg and Seltzer, (2011). At the same time, it the insufficient awareness of parents about the idea of an independent life and the inconsistency between adolescents' ability during household activities and their subjective perceptions can be stated, as well as the overprotection and over caring, one of the Armenian traditional cultural features, which had its effect on response rates.

Analyzing the responses of the respondents and comments it is concluded that the majority of parents are of the opinion that their adolescents, if not fully, then at least partially can be involved in the performance of lifestyle activities. According to some researchers, it is crucial for a person with a disability to be able to be independent, to have adapted and adjusted environment based on his/her needs (Livingston, Rosenbaum, Russell & Palisano, 2007). Also, the authors outline the main role of participation and self-satisfaction, predominantly quality of life, independent living and health-related quality of life (Jemtå, 2008).

According to some sources, the specialists who work with adolescents need to know what is normative and what represents early or late physical development in order to help prepare the adolescent for the myriad changes that take place during this time of life (APA, 2002; Coleman & Hendry, 1999). In this regard, within this context, it is important also to know cultural peculiarities and organize work not only with children in order to improve or develop necessary social and household skills, but also to help parents to overcome difficulties and changing mindsets regarding overprotection of their child, in order to help them to become independent.

Occupational therapists have always used the involvement of parents in the planning and decision-making process of their children's intervention. The latest trends in paediatrics are directed towards a family-centred approach, and the central component of this approach is the cooperation of parents, occupational therapists in the process of organizing the assessment and intervention of the child (Hanna & Rodger, 2002). This very important standpoint should be taken into account and implemented for support to parents and adolescence with mobility disorders as well as for raising their awareness regarding the possibilities of their children.

CONCLUSION

According to the survey results, it is possible to conclude that parents of adolescence with mobility disorders prioritize independent life for their children. The need to teach their adolescence social and household skills such as shopping, cooking, kitchen utensils, cleaning the area, and helping with household chores has also become so important.

Of course, the results are quite gratifying, as they show the gradual decline of the once prevalent stereotypes in the Armenian society, especially among children or adolescence and parents of children with disabilities, when people with disabilities were seen as a vulnerable minority. At the same time, it might be stated that there is a lack of awareness of parents about the idea of living an independent life, as well as the inconsistency of adolescents' ability to carry out household activities, their incompatibility with parents' subjective perceptions exists. And at last, the traditional Armenian cultural peculiarities, the predominance of overprotection should be mentioned as an important factor in regard to research results, as well as interconnected with the effect on the response rates.

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