

Future perspectives on the social participation of adolescents with cerebral palsy and their mothers

Perspectivas futuras sobre participação social na ótica de adolescentes com paralisia cerebral e suas mães

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ABSTRACT: *Aim:* To understand the future aspirations regarding the social participation of adolescents with CP, from the perspective of the adolescents and their families. *Method:* This exploratory study used a qualitative methodology. The participants were seven adolescents with CP (aged from 11 to 17 years old) and their mothers. For collecting data, it was used two semi-structured interview script, a descriptive questionnaire and the GMFCS Gross Motor Function Classification System – Family Report Questionnaire. Data from interviews were analyzed through the methodology of the Collective Subject Discourse. *Results:* The main results indicated that the adolescent's wishes and hopes about their social participation in the future are related to professional career, to future studies and to a close relationship with family and friends. Mothers evidenced concerns about issues of the adolescence, such as involvement with peers, dating, challenging parental practices and self-affirmation, and their expectations regarding to the future of their children, such as financial independence and autonomy. *Conclusion:* It is expected that this study provides elements for occupational therapist's practices that aim at expanding and strengthening the social participation of adolescents with CP.

KEYWORDS: Cerebral palsy; Adolescents; Social participation; Future; Family; Occupational therapy.

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RESUMO: *Objetivo:* Conhecer as perspectivas futuras em relação a participação social de adolescentes com Paralisia Cerebral, sob a ótica dos próprios adolescentes e de seus familiares. *Método:* Trata-se de um estudo exploratório de abordagem qualitativa. Participaram 7 adolescentes com PC, com idade entre 11 e 17 anos, e suas mães. Foram utilizados, para a coleta de dados, dois roteiros de entrevista semiestruturada, um formulário de identificação e o GMFCS Sistema de Classificação da Função Motora Grossa – Questionário do Relato Familiar. Os dados gerados a partir das entrevistas foram analisados através da metodologia do Discurso do Sujeito Coletivo. *Resultados:* Os principais resultados indicaram que os adolescentes desejam seguir uma carreira profissional, continuarem estudando e estarem perto da família e de amigos. Em relação às mães, estas demonstraram preocupações com o surgimento de questões da adolescência, como o envolvimento com pares, namoros, questionamento das práticas parentais e autoafirmação e suas expectativas em relação ao futuro dos filhos como a independência financeira e autonomia. *Conclusão:* Compreende-se que a presente pesquisa fornece elementos para intervenções terapêuticas ocupacionais que visam a ampliação e o fortalecimento da participação social de adolescentes com PC.

DESCRIPTORES: Paralisia cerebral; Adolescentes; Participação social; Futuro; Família; Terapia ocupacional.

This study is linked to a broader master's research developed in the UFSCar Graduate Studies Program in Occupational Therapy and it is entitled as "Parenting, Participation and Social Support: giving voice to adolescents with cerebral palsy and their mothers", developed by the authors of this study.

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BACKGROUND

Cerebral Palsy (CP) is described as a group of permanent disorders of the development of movement and posture which are attributed to non-progressive disorders that occur during fetal development or in the infant brain¹. It is known that CP is the most common cause of physical disability in childhood with a prevalence of 2 to 2.5 per 1000 births worldwide^{1,2}.

Among difficulties that children and adolescents with CP experience it is highlighted the problems related to mobility, problem solving, socialization and communication that cause limitations in activities. In addition, this population is at risk of a lower participation in social and leisure activities, which are crucial to develop friendships, interests and promoting well-being³.

Participation in social activities for adolescents with disabilities and chronic health conditions have gained a little more attention in recent years^{3,4}. However, the literature has indicated a gap in the knowledge regarding the understanding about the way and the intensity children and adolescents with physical disabilities have the opportunity to be involved and to enjoy leisure activities at home and in the community, revealing that this still is an emerging area of research^{5,6}. Therefore, it is highlighted that social participation is a complex phenomenon that needs to be studied more in depth⁷ and we reinforce the need of further research that may enhance the knowledge about this population^{3,8}.

In addition, it is reinforced that, although the research on adolescence and the transition to adulthood by young people with CP have grown in recent decades, there are still many elements not understood in relation to their social participation^{7,9}. Nevertheless, it has been shown that social participation is associated with the promotion of health, social behaviors and other positive results for adolescents⁷.

Recent studies have pointed that when the family tends to treat children and adolescents with disabilities in the same way as other family members, they tend to feel safer, with greater social participation and with a higher perception of quality of life^{10,11}.

During adolescence, social participation prepares adolescents for important aspects of adulthood such as work, marriage and leisure, furthermore social

participation allows adolescents to expand their social network with people who do not belong to the family's context or to the school routine, and these experiences are important for skills development and for fulfilling adult roles¹².

The literature has indicated that adolescents with CP need to have the opportunity to discuss their feelings, fears and expectations about the future, since they are in a continuous process of change of the way they see and define themselves¹³.

Cussen et al.¹³, through a qualitative research conducted in Australia, aimed to understand the expectations and hopes of adolescents with CP about the future. The results have shown that the adolescents expressed the desire of being close to family, friends and pets, to plan their professional careers, to live independently at their home, and to make a trip at a future time. The researchers reinforced the relevance of seeking information from the perspective of the adolescents themselves since this make it possible to support their expectations.

Therefore, it is reinforced that to understand the problems and challenges that adolescents with disabilities find in their way into adult life, it is necessary to address the perspectives of adolescents with CP and their families.

Furthermore, it is understood that this knowledge could be used by occupational therapists and other professionals who work with adolescents to significantly expand and promote their psychosocial development⁵.

AIM

This study aimed to comprehend the future perspectives regarding the social participation of adolescents with CP, from the perspective of adolescents themselves and their mothers.

METHOD

This is an exploratory, descriptive, cross-sectional study with a qualitative approach. This study is linked to a master's research developed in the UFSCar Graduate Studies Program in Occupational Therapy and it is entitled as "*Parenting, Participation and Social Support: giving voice to adolescents with cerebral palsy and their mothers*", developed by the authors of this study.

Participants

The participants of this study were 7 adolescents with CP, aged 11 to 17 years and their mothers. Sample was intentionally chosen using a purposeful convenience sampling method¹⁴.

As criteria for participation in this study, it was recommended that family members should reside with adolescents with CP for at least 3 years and adolescents should have Cerebral Palsy diagnosis reported by healthcare providers or education professionals.

Local

This study was carried out in a medium size city in the Midwestern region of the state of São Paulo, Brazil, with a population of approximately 241,389 inhabitants¹⁵. Interviews were conducted at the participants' homes, except for two participants who preferred to be interviewed at the school where they were attending.

Measures

A questionnaire was applied to mothers to characterize their socioeconomic profile and to obtain general information, such as schooling, marital status, number of children.

The Brazilian version of the *GMFCS Family Report Questionnaire*¹⁶ was also used to identify the participants' level of gross motor function, considering mobility restrictions and thus characterizing them in terms of different levels of functionality.

In order to know the future perspectives regarding the social participation of adolescents with CP, two semi-structured interview scripts were elaborated. The adolescents answered four questions about their future, projects, dreams, and challenges. The adolescents' mothers were invited to answer questions related to their expectations about their children's future and to their future challenges as parents.

Procedures

The adolescents were indicated by a healthcare provider from the rehabilitation center where they were attended. After presenting the objectives of the study, the researcher invited the adolescents and their caregivers to participate. The adolescents who agreed

to participate were then individually interviewed as well as their guardians, all represented by mothers.

Ethical Procedures

This study was submitted to the analysis of the Human Research Ethics Committee of UFSCar and approved, with ethical clearance number of 794.535.

Data Analysis

Interviews were audio-recorded and transcribed verbatim.

Data were analyzed qualitatively using the Collective Subject Discourse (DSC) method. This method has been successfully used worldwide in several studies in different areas of knowledge such as health and education. Based on the Theory of Social Representation, the DSC involves the junction, through discourses-syntheses, of the contents and arguments that conform similar opinions, which allows the representation of the opinion of a collective, through a single discourse without losing the essentially discursive and qualitative nature of an opinion. Thus, the DSC consists of a group of operations that results in collective discourses which are made from literal extracts of the most significant contents from different discourses with similar meaning^{17,18}.

RESULTS

Socioeconomic data and general information on the participants' profile as well as the GMFCS classification are described in Tables 1 and 2 below:

As it can be seen in Table 1, 4 participants were aged between 14 and 15 years old, and only 1 participant was 17 years old.

Of the 7 adolescents 6 are enrolled in the regular education and only 1 attends special school only.

In addition, among the 7 participants, 6 are currently attending weekly specialized therapies such as Physiotherapy and Occupational Therapy and only 1 adolescent is not attending therapies.

Regarding to gross motor function, GMFCS ranged from levels I and II, with 3 participants, to IV and V, with 4 participants.

The mother's profile is described in Table 2 below:

Chart 1 – Profile of the adolescents participants of this study

	Age in years	Gender	Scholarity	Kind of school	Educational path	GMFCS level*	Attending any treatments
A1	11	Male	Attending the 5th year of elementary school	Regular municipal school	Always studied in a regular school	II	Physiotherapy and Occupational Therapy
A2	17	Male	Attending the 8th year of middle school	Private special school	Studied in a regular school	IV	Physiotherapy and Occupational Therapy
A3	11	Female	Attending the 5th year of elementary school	Regular municipal school	Always studied in a regular school	IV	Physiotherapy and Occupational Therapy
A4	15	Female	Attending the 8th year of middle school	Regular municipal school and private special school	Always studied in a regular school and has been attending special school for 2 years	IV	Physiotherapy, Hydrotherapy and Occupational Therapy
A5	14	Female	Attending the 1st year of high school	Regular state school	Always studied in a regular school	I	Physiotherapy
A6	14	Female	Attending the 9th year of middle school	Regular state school	Always studied in a regular school	II	Physiotherapy
A7	15	Female	Attending the 8th year of middle school	Regular state school	Studied for 4 years in a special school and then started attending a regular school	V	—

*According to the Gross Motor Function Classification System for Cerebral Palsy - GMFCS.

Chart 2 – Profile of the Mothers participants of this study

	Age in years	Profession	Scholarity	Marital Status	Number of children	Family income in minimum wages*
M1	29	Housewife	Incomplete middle school	Married	3	1-2
M2	54	Housewife	Incomplete middle school	Widow	5	6-8
M3	28	Housewife	Complete middle school	Married	3	2-4
M4	52	Housewife	Complete high school	Married	3	2-4
M5	53	Dealer	Complete middle school	Married	4	4-6
M6	47	Contract Manager	University graduate	Married	2	4-6
M7	38	Housewife	Incomplete middle school	Divorced	3	1-2

Nota: *current minimum wage on the period of data capture = R\$ 724,00

The main results of this study are presented below. Firstly, it is presented the DSCs generated from the interviews with the adolescents with CP and next it is presented the DSCs from the mother's interviews.

Future Perspectives on Social Participation from the point of view of adolescents

Through the adolescent's discourses it is possible identify positivity in their perspectives about the future, they also reflect on what will be important to their quality of life. The adolescents emphasized the importance of establishing a professional career, of continuing to study and being close to family and friends.

"I actually think it's going to be a successful future, I dream of graduating, going to college, having a profession. I'll never stop studying, so I have to work hard".

"For me, (quality of life is everything). I think it is about having great knowledge to get a job, because nowadays if you do not have qualifications you do not get a job. Thus a nice job, money, happiness, good friends and family, reliable people around us".

"I do not know. I find it a bit difficult to answer."

When asked about their dreams for their future, the adolescents expressed different desires and reported the strategies they considered for achieving their goals, as the following discourses reveal:

"I dream of graduating, making another graduation and then taking a course, I still did not give up on this dream".

"I dream of traveling from Brazil to abroad".

"I think I will go for it, I have to move on, work and study hard, really hard. Then I get it".

Future Perspectives on Social Participation from the point of view of mothers of adolescents with CP

In order to obtain a broader view about the perspectives on the future and social participation of adolescents with CP, the adolescent's mothers were asked to share their opinion. Therefore, different aspects emerged

and it is highlighted the future expectations related to raise their adolescents.

Thus, mothers showed concerns about the emergence of issues inherent to adolescence, such as involvement with peers, dating, questioning of parental practices and self-affirmation. In addition, mothers expressed the need to follow the maturation process of their children and reinforce the learning of moral values considered important. Following, some discourses that portray these issues are presented:

"From now on, for me, it is necessary to keep up with him as he moves on to adulthood, and to act according to his time ... I will not have that child's phase, baby's phase, it has passed, now I have to continue".

"Now, the adolescence is coming and she is noticing more things around her, which is now very difficult [...], she is growing and thinks that she is very grown up, she thinks that she is already too capable for doing things. Now, she wants to copy girls around her, and I have to think that now I have an adolescent daughter at home. This kind of thing, such as going out with her friends, how I'm going to handle it if she wants to go, it's going to be difficult".

"Uh, we need a more firm attitude [...] They have to understand that when you say no, it is not easy to say, but it is for their own good, then it is more complicated, until now you have dominated, but they are reaching an age and they think they can do anything, but we live day after day and try to make it smother... I think we need to be patient".

In addition, mothers have shown great concern related to help their children to prepare for high education and good employment in order to ensure financial independence and a good future for them. As illustrated by the following discourses:

"Now regarding to the future I think that I'm anxious about it, I say she'll have to take care of herself [...] So I worry about her financial situation [...] we joke with her and tell her [...] to study hard because when you have a public job and you're old you're going to do [...] I do not imagine she's going to be unable, [...] that she's going to live on retirement because she's disabled. I have never thought about it! [...] we look for her physical and psychological independence [...]".

"Oh yeah, there's going to be plenty of things to do with him, so he can have a better education, especially [...] for him not to be in those kind of life that a lot of people have out there, so the concern will be greater".

DISCUSSION

Through the adolescent's discourses, it is understood that their aspirations and wishes for the future life reflect typical characteristics of the adolescence itself. The adolescents have demonstrated that they have plans for the future and for adult life, they set goals, have dreams and expectations.

Under this perspective the literature indicates that transition from adolescence to adulthood can be considered as a critical period of development, since adolescents need to make several decisions that reflect their autonomy in different areas of life such as work, continuing studies, leisure, health care, social interaction and community participation¹⁹. Thus, the results of the present study reinforce this understanding since the participants of this research have expressed similar concerns regarding to these factors.

In addition, it is important to highlight that although it is important to know what adolescents with physical disabilities want for their lives, it is also essential to understand the factors that can help or hinder this trajectory. Without this understanding, professionals working with this population can make erroneous assumptions about what is important to these adolescents and what factors could help them on the road to adulthood²⁰.

King et al.²⁰, in research carried out in Canada about the desires and life goals of adolescents with CP, interviewed 10 adolescents aged between 18 and 20 years old, in the transition from high school to college or entering into the job. In this study, participants were asked to define what is success in life, what they thought about who they would be in the future, and the factors that helped or hindered them to be successful. The results indicated that success meant being happy. In addition, three psychosocial factors were related to achieving success and happiness in life: to believe in themselves, to realize that others also trust in their potential and to be accepted by others. As such, it is believed that the results of the present study confirm the findings of King²⁰, and we reinforce that adolescents when talking about their aspirations for the future and their desires for participation demonstrate to value similar elements.

Other important aspects highlighted on the adolescent's discourses were the expression of their desires regarding their progress on education, establishing a professional career and being close to their families and loved ones.

These findings are in line with the results of Cussen et al.¹³ which have indicated three themes related to expectations of adolescents with CP for the future: to maintain intimate relationships, to choose the future life for themselves and the leisure aimed for the next years. Under these themes, the adolescents also expressed the desire to be close to family, friends and their pets, to plan a professional career, to live at home independently and to take a trip in the future. In addition, Cussen et al.¹³ also stressed the importance of seeking information from the adolescents themselves so that the expectations of the adolescents can be supported, what is reinforced by the results of the present study.

In the present study, a relevant aspect that deserves to be highlighted is regarding to the adolescent's future expectations and the impairment of gross motor function. It is important to highlight that, although in this study the adolescents had different levels of motor impairment, the results showed a great similarity in aspirations for the future and in social participation, compared to adolescents with typical development. These results reinforce the findings of Tan et al.²¹ which indicated that impairment of gross motor function may not be directly associated with social participation and future perspectives.

It is also emphasized that adolescents have strongly indicated the importance and necessity of studies in their lives. It is hypothesized that the insertion of these adolescents from an early age into regular education could have been an important factor for promoting the social participation of these adolescents, and may also have influenced their projects for future life.

Regarding the mother's discourses, it is observed that mothers follow the maturing process of their children, and that this requires changes in the way they relate to them. The mothers emphasized the concern to maintain the firmness in the education of their children, although they understand that at this stage they will be more likely to challenge the boundaries and they will seek to have greater autonomy.

It should be highlighted that maternal discourses did not refer to issues related only to disability, but rather reflected family concerns related to adolescence²². It is also important to highlight that mothers were sensitive

to recognize the challenges of this phase and, at the same time, reaffirmed the posture of following their children in this new period, respecting their subjectivities and needs.

Therefore, it is understood that the findings of the present study corroborate to the understanding that it is necessary for family to make new arrangements in order to allow the independence of their adolescent children and to live with tranquility this process of entering and leaving the family system^{22,23}.

Through the mother's discourses presented, it is understood that the results of the present study are consistent with the findings of Antle et al.¹⁰ which indicated that the majority of parents of adolescents with CP had concerns about the future of their children such as opportunities to continue their studies, establish a career, be financially independent, and live their lives for their own.

Under this perspective, it is understood that in the present study mothers shared similar concerns, as they also assumed the responsibility of helping their children in this journey for independence and personal growth.

It is emphasized that when talking about the future of their children, mothers have demonstrated that they and their families as a whole will also undergo the transition process. Therefore, the literature has shown that it is necessary to understand that the transitions impact both adolescents and their families²⁴. Thus, parents may experience stress from the onset of a new stage in their children's lives and may experience a difficult emotional time when they see that their expectations about the future of their children being were frustrated^{24,25}.

As such, although the mothers have expressed themselves about the strategies they intend to use, they may require support and spaces for sharing, which can be made available by professionals or services that

accompany these families. Therefore, it is important that these demands are considered in the scope of research, and new studies are needed to investigate how support factors can be better implemented in the transition, as well as in proposing practices in services that serve this population.

FINAL CONSIDERATIONS

It is considered that the present study contemplated the desired goals, as it provided elements for understanding the future perspectives regarding the social participation of adolescents with CP from the perspective of both adolescents and their mothers.

It is also emphasized that, regarding the expectations of these adolescents related to their occupational engagement and social participation in the future, this study provides elements that should contribute to answer the gaps of the national and international literature on this area of research and it provides a progress, since there are few studies that give voice to adolescents and therefore they can tell their aspirations and desires for the future life.

In this study it was revealed that adolescents emphasize the importance of studying, establishing a career and having a family, as perspectives for their lives in the future. However, it is suggested that future studies involving a greater number of participants and considering the factors that may help or hinder the implementation of future projects and the social participation, which may mediate the social support, are taken

Thus, it is understood that this research contributes to the enhancement of knowledge in this area and provides subsidies for therapeutic interventions aimed at expanding and strengthening the social participation of this population.

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