ORIGINAL RESEARCH

Cross-cultural adaptation of the Rotterdam Transition Profile to Brazilian Portuguese: measuring autonomy in participation of Brazilian youth with cerebral palsy

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Abstract

Background: Autonomy in participation of young adults with cerebral palsy (CP) is not well understood due to the lack of appropriate instruments, especially for the Brazilian population. The Rotterdam Transition Profile (RTP) categorizes autonomy in Participation (education, employment, finances, housing, leisure, intimate relationships, sexuality, transport) and Health Services (care demands, services and aids, and rehabilitation services) domains.

Objectives: To cross-culturally adapt the RTP for use in Brazil, and to describe the levels of autonomy in participation and associated factors of Brazilian youth with CP.

Methods: RTP was translated and content validity was investigated through an expert panel (n = 4 researchers and n = 4 clinicians); 30 adolescents and young adults with CP provided data for construct validity and internal consistency analysis. To analyze influencing factors, 56 youth with CP, mean age 25 years (SD = 6.9 years), with good cognitive level remotely responded to the RTP, sociodemographic information, and functional classifications (gross motor, manual ability).

Results: Following translation, content and construct validity were established, with changes made to improve the clarity of items. Cronbach’s alpha (0.82) was considered good and test-reliability was fair to good for most items. High levels of autonomy were found in the areas of Leisure and Rehabilitation, with the lowest proportion of participants with autonomy in Housing, Intimate Relationships, and Finances. Autonomy in participation was associated with age, gross motor and manual ability classifications, and with context-related factors.

Conclusion: The Brazilian Portuguese version of the RTP was considered valid and reliable. Findings will support transition planning for young people with CP.

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Keywords: Autonomy; Cerebral palsy; Participation; Transition to adulthood

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Introduction

Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation. With increasing life expectancy, individuals with CP are reaching adulthood in greater proportions. Currently, more than 90% of individuals with CP are living beyond the age of 18 years. Under these circumstances, understanding their transition to adulthood becomes a relevant aspect.

Transitions are points between developmental stages that are accompanied by changes in the environment or demands for new skills. For adolescents, this means moving towards independence in finances, housing, and relationships, among other areas. However, during the transition to adulthood, a significant number of adolescents and young adults with CP have restrictions in participating autonomously in several aspects of life. Studies show that they participate less in experiences such as living alone, having a paid job, and in romantic and sexual relationships than typically developing individuals.

To understand the development of autonomy in participation, youths must speak for themselves, as their perception often differs from the perception of caregivers. The Rotterdam Transition Profile (RTP) was developed to assess autonomy in participation in several life areas during the transition to adulthood of youths with chronic health conditions. Originally developed in the Netherlands using the Dutch language, the RTP was translated into English and is currently used in transition research.

Research using the RTP has shown that youths with CP have less autonomy in participation in employment, finances, housing, romantic relationships, sexuality, and transportation than their typical peers. RTP results are associated with the levels of gross motor and manual function, education, daily activities, and participation. Challenges in acquiring autonomy during transition to adulthood may result in unemployment, lack of personal fulfillment, and low quality of life.

However, the literature on the acquisition of autonomy in participation is still incipient. This is especially true regarding the Brazilian population, mainly due to the lack of research targeting this life stage and the lack of tools to assess this outcome. Therefore, this study aims 1) to cross-culturally adapt the RTP questionnaire; 2) to characterize the levels of autonomy in participation of Brazilian youth with CP; and 3) to explore associations between the RTP and functional level, gender, age, and educational level. The results will make the RTP available for use in Brazil, and provide preliminary insights on the levels of autonomy in participation of youths with CP, and their associated factors.

Methods

Design

Observational study with a cross-sectional design, conducted from 2020 to 2023.

Participants

The validation stage included healthcare professionals and youth with CP. Youth with CP participated if they had a diagnosis of CP, cognitive ability to comprehend simple to medium-complexity questions, were between 13 and 38 years of age, and able to communicate independently or with minimal assistance. Mini-Mental State Examination (MMSE) above the cut-off value of 30 points for individuals 13—16 years of age and 27 points for those older than 16 years ensured participants’ cognitive level. This study was approved by the Research Ethics Committee of the Federal University of São Carlos (case number 40161720.1.0000.5504). All adult participants provided informed consent, and for adolescents under 18 years of age, consent and assent were obtained from guardians and participants, respectively.

Cross-cultural adaptation

Cross-cultural translation followed standardized methods. In 2020, the RTP authors were contacted and agreed to an official translation. The English version of the instrument was translated into Brazilian Portuguese in 2021. The translation process involved three translators (two physical therapists and one occupational therapist) fluent in the English language and with more than one year of experience abroad, all with expertise in neurofunctional rehabilitation, CP, adolescence, and transition to adulthood. First, two translators independently translated the RTP. After discussions, a unique translated version of the instrument was generated (forward translation). Then, this version was back translated into English by the third translator, who was naïve to the instrument. The original version, the translated and back translated versions were sent to the authors for feedback.

For construct validity, eight physical therapists with clinical and academic experience in the field of pediatric rehabilitation joined the expert panel, which is consistent with the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) of at least seven professionals for very good study quality. These professionals were chosen by convenience and expertise with the study population and cross-cultural adaptation methods. Details about the expert panel are available in Supplementary material 1. An online form containing instructions and the Brazilian Portuguese version of the PTR was sent to the experts. On the form, each item of the instrument was accompanied by a question about the clarity and adequacy of the terms for Brazilian culture.

Next, content validation was performed with 30 youths with CP, a sample size considered adequate for content validity studies. Participants were interviewed with the RTP-Brazilian Portuguese version and were asked about the clarity and suggestions for each item. Subsequently, all the suggestions were analyzed by the researchers. A subset of 16 participants responded to this questionnaire once again for reliability test within an average 61 days (SD = 30) days from the first assessment. These stages were completed between 2022 and 2023.

Study instruments

The 30 youths with CP who participated in content validation, and an additional 26 youths with CP completed the following instruments, presented by the first and second authors in individual Google Meet sessions, in the following order:

Sociodemographic questionnaire: collected information about age, gender, education of the individual and the main...
caregiver, source of income, monthly household income, housing, and region where they live.

Classification systems: manual skills were assessed by interview using the Manual Ability Classification System (MACS).25 and The Gross Motor Function Classification System (GMFCS-self report) was sent by email to be completed independently by the youths.26,27

Participants took an average of 30 min to complete each questionnaire. Rotterdam transition profile: RTP assesses the development of autonomy in participation in various aspects of life and in the use of health services according to 10 domains divided into 2 components: 1- Participation (seven domains: education and employment; finances, housing, social activities, intimate relationships, sexuality, and transportation) and 2- Health services (three domains: demand for care, services and support, and rehabilitation services).9

The scores range from 0 to 3 or 1–3 points, as follows: 0- no experience; 1- dependent on others; 2- experiencing autonomy and orienting oneself to the future; and 3- acquired autonomy. There is no total score or summary of scores, thus the RTP results consist of the individual score in each of the 10 domains. The original and English versions of the RTP have been validated for the CP population without cognitive impairments and are suitable for use in a wide age-range. Reliability data have not been published.9,12,14

The average RTP application time was between 20 and 30 min, depending on the participant’s cognitive level and flux of conversation.

The RTP was completed in an interview format initially with a total of 30 young people with CP.

Data analysis

Sociodemographic data, functional classification, and autonomy in participation were reported descriptively. Internal consistency was assessed through Cronbach’s alpha values considering all respondents (n = 30). Spearman’s correlation tests explored associations between all RTP variables and age. Partial rank correlation tests correcting for age were used to investigate associations with the RTP areas. For the interpretation of correlation coefficients, a value of 0.1 indicated a weak correlation, 0.3 a moderate correlation, and 0.5 a strong correlation.28 Test-retest reliability data (n = 16) were obtained through linear weighted Kappa and interpreted according to Fleiss, where <0.40 indicates low agreement, 0.40–0.75 fair to good agreement, and ≥0.75 excellent agreement.29,30 Data were analyzed using the Statistical Package for Social Sciences (SPSS) version 21.0 for Windows, considering a significance level of 0.05.

Results

In total, 56 youth with CP participated in the study (Table 1). There were at least three representatives from each geographic region of Brazil.

RTP translation

During the translation process, most of the terms and definitions used in Portuguese matched the original terms in English. The authors checked the back translated version and the Brazilian Portuguese version, provided insights on the translation, and specified some terms to be sure that the original meaning was kept. Some words were kept to be more consistent with the original English term. A final Brazilian Portuguese version was defined and approved after two review rounds with the authors.

RTP validation process

Construct validity

The terms with the largest number of suggestions were “education and employment”, with suggestions from five of the eight professionals to better specify the term “educação geral” (general education); “Care demands”, with four suggestions for replacing the word “formulam” (formulate); and “Services and products”, with five professionals requesting examples of health services and products. No modifications were made to the terms “educação geral” (general education) and “formulam” (formulate), as the authors of the instrument asked to keep the terms defined during the translation process, considering those closer to the original terms in English. No changes were made on “Services and Products” either, as examiners can provide examples of services and products commonly provided to facilitate the comprehension, if necessary.

Table 1 Clinical and sociodemographic characteristics of the sample.

<table>
<thead>
<tr>
<th>Sample characteristics</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Female = 32; Male = 24</td>
</tr>
<tr>
<td>Age</td>
<td>Mean = 24.98; SD = 6.9y</td>
</tr>
<tr>
<td>Brazilian region of origin</td>
<td>SE = 35; NE = 7; S = 6;</td>
</tr>
<tr>
<td></td>
<td>CW = 5; N = 3</td>
</tr>
<tr>
<td>Participants’ educational level</td>
<td>Basic Education = 32;</td>
</tr>
<tr>
<td></td>
<td>Profes. Education = 24</td>
</tr>
<tr>
<td>Parents’ educational level</td>
<td>Basic Education = 29;</td>
</tr>
<tr>
<td></td>
<td>Profes. Education = 27</td>
</tr>
<tr>
<td>Has own income</td>
<td>Yes = 33; No = 23</td>
</tr>
<tr>
<td>Housing status</td>
<td>Owner = 44; Renter = 8;</td>
</tr>
<tr>
<td></td>
<td>Borrower = 4</td>
</tr>
<tr>
<td>Family monthly income*</td>
<td>Mean = 4.59; SD = 2.9</td>
</tr>
<tr>
<td></td>
<td>minimum wages</td>
</tr>
<tr>
<td>MACS Level</td>
<td>I = 20; II = 14; III = 16;</td>
</tr>
<tr>
<td></td>
<td>IV = 4; V = 2</td>
</tr>
<tr>
<td>GMFCS Level</td>
<td>I = 7; II = 11; III = 17;</td>
</tr>
<tr>
<td></td>
<td>IV = 18; V = 3</td>
</tr>
</tbody>
</table>

* 1 minimum wage corresponds to approximately USD229.00.

The original and English versions of the RTP were matched by the authors, with four suggestions for replacing the word “formulam” (formulate); and “Services and products”, with five professionals requesting examples of health services and products.

During the translation process, most of the terms and definitions used in Portuguese matched the original terms in English. The authors checked the back translated version and the Brazilian Portuguese version, provided insights on the translation, and specified some terms to be sure that the original meaning was kept. Some words were kept to be more consistent with the original English term. A final Brazilian Portuguese version was defined and approved after two review rounds with the authors.

RTP validation process

Construct validity

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Content validity

Despite good overall satisfaction and comprehension of the RTP Portuguese version by the experts and youth with CP, both groups indicated some common unclear terms, which was a strong indicator that adaptations were needed. In total, six terms had suggestions for change, of which two (33.33%) were modified, as they were recommended by professionals and youths with CP.

The items containing terms with the largest number of suggestions for change were “education and employment” (item one) and “care demands” (item eight), with 12 and nine suggested changes, respectively. For item one, the suggestions were to revise “treinamento vocacional” (vocational training), which was then replaced by “treinamento profissional” (professional training). Also in this item, the suggestion to specify the term “educação geral” (general education), led us to replace it with “Educação básica” (Basic education). In item eight, the word “formulam” (formulate) was replaced by “Percebem e expressam” (Perceive and express).

On item two, “finances”, there were suggestions to replace the term “mesada” (pocket money) for another term, however, no changes were made due to the lack of another equivalent term. On item four, “leisure”, no changes were made to maintain the original. The final version of the RTP after the validation process is available in Supplementary material 2 and the complete translation and validation process of the RTP to Brazilian Portuguese is detailed in Supplementary material 3.

RTP internal consistency analysis resulted in Cronbach’s alpha value of 0.820, which indicates good consistency. Most items were classified as fair to good on the test-retest reliability procedure (Table 2). The items of “housing”, “care demands”, and “rehabilitation” showed low test-retest reliability, and the sexuality item had excellent reliability.

Factors related to autonomy in participation

Spearman tests showed strong to moderate positive correlations between participants’ age and autonomy in sexuality ($r = 0.640; p < 0.01$), education and employment ($r = 0.499; p < 0.01$), services and aids ($r = 0.456; p < 0.01$), leisure ($r = 0.437; p < 0.01$), intimate relationships ($r = 0.437; p < 0.01$), transportation ($r = 0.422; p < 0.01$), and finances ($r = 0.369; p < 0.05$). Positive weak correlations were found between age and autonomy in care demands ($r = 0.295; p < 0.05$).

Partial correlation tests indicated weak to moderate associations between RTP and caregiver and participant’s education, GMFCS, MACS, and family income (Table 4).

Discussion

The RTP is an innovative instrument available to categorize the autonomy in participation of youth with CP, in different life areas. Increasing clinical and research interest in supporting the transition to adulthood demands new tools such as the RTP to become available.

When translating tools, balancing the literal and the conceptual meaning of the content is a challenge, as some expressions may not have an exact substitute in other languages or may be unusual. When adapting a tool to another language, efforts are needed to minimize misunderstandings, as this can lead to inaccurate interpretations. Thus, special attention was paid to the feedback from the final users during the validation. Internal consistency was considered good, with the same test-retest reliability of most items, which is a positive indication of adequacy of the RTP Portuguese version.

Low reliability in specific items may be due to the sample size being lower than what is recommended by COSMIN. Additionally, when looking at individual results, we noticed that most of the changes from test-retest were towards a lower level of autonomy, i.e., unlikely to be explained by developmental changes. It is possible that some youths have never reflected about their autonomy, or perhaps felt embarrassed to demonstrate low autonomy when interviewed. These observations warrant further investigation of RTP reliability and stimulate additional research to

Autonomy in participation

Autonomy in participation was achieved for most participants in the areas of leisure (73.2%) and rehabilitation services (69.6%). The levels of autonomy for each domain are shown in Table 3.

Table 2 Test-retest reliability of the Brazilian version of the Rotterdam Transition Profile.

<table>
<thead>
<tr>
<th>RTP Item</th>
<th>Weighted Kappa</th>
<th>95% CI</th>
<th>Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>1- Education and employment</td>
<td>0.74</td>
<td>0.44, 1.03</td>
<td>fair to good</td>
</tr>
<tr>
<td>2- Finances</td>
<td>0.69</td>
<td>0.43, 0.95</td>
<td>fair to good</td>
</tr>
<tr>
<td>3- Housing</td>
<td>0.25</td>
<td>-0.21, 0.71</td>
<td>low</td>
</tr>
<tr>
<td>4- Leisure</td>
<td>0.60</td>
<td>0.37, 0.83</td>
<td>fair to good</td>
</tr>
<tr>
<td>5- Intimate relationships</td>
<td>0.75</td>
<td>0.46, 1.02</td>
<td>fair to good</td>
</tr>
<tr>
<td>6- Sexuality</td>
<td>0.90</td>
<td>0.77, 1.04</td>
<td>excellent</td>
</tr>
<tr>
<td>7- Transportation</td>
<td>0.63</td>
<td>0.32, 0.94</td>
<td>fair to good</td>
</tr>
<tr>
<td>8- Care demands</td>
<td>0.33</td>
<td>-0.03, 0.69</td>
<td>low</td>
</tr>
<tr>
<td>9- Services and aids</td>
<td>0.72</td>
<td>0.47, 0.96</td>
<td>fair to good</td>
</tr>
<tr>
<td>10- Rehabilitation services</td>
<td>0.30</td>
<td>-0.09, 0.69</td>
<td>low</td>
</tr>
</tbody>
</table>

95% CI, 95% confidence interval; RTP, Rotterdam Transition Profile.
<table>
<thead>
<tr>
<th>Autonomy level</th>
<th>RTP Item</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>Median (Min- Max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1- Education and employment</td>
<td>N = 0 (0 %)</td>
<td>No experience</td>
<td>N = 11 (19.6 %)</td>
<td>N = 24 (42.9 %)</td>
<td>N = 21 (37.5 %)</td>
<td>2 (1–3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Follows no education, no job</td>
<td>General education</td>
<td>Vocational training, work placement</td>
<td>Paid job, volunteer work</td>
<td>2 (1–3)</td>
</tr>
<tr>
<td>2- Finances</td>
<td>N = 13 (23.2 %)</td>
<td>No pocket money, fully economically dependent</td>
<td>N = 12 (21.4 %)</td>
<td>N = 9 (16.1 %)</td>
<td>Job on the side, student grant</td>
<td>N = 22 (39.3 %)</td>
</tr>
<tr>
<td>3- Housing</td>
<td>–</td>
<td>Lives with parents or caregivers, not responsible for household activities</td>
<td>N = 26 (46.4 %)</td>
<td>Partly responsible for household activities, domestic training, or seeking independent housing</td>
<td>N = 6 (10.7 %)</td>
<td>Lives independently</td>
</tr>
<tr>
<td>4- Leisure (social activities)</td>
<td>N = 2 (3.6 %)</td>
<td>Does not arrange any leisure activities with peers</td>
<td>N = 2 (3.6 %)</td>
<td>Arranges leisure activities with peers outside the home during daytime</td>
<td>Arranges leisure activities with peers</td>
<td>N = 21 (37.5 %)</td>
</tr>
<tr>
<td>5- Intimate relationships</td>
<td>N = 16 (28.6 %)</td>
<td>No experience with dating</td>
<td>N = 11 (19.6 %)</td>
<td>Experience with dating but not yet with courtship</td>
<td>Experience with courtship</td>
<td>N = 21 (37.5 %)</td>
</tr>
<tr>
<td>6- Sexuality</td>
<td>N = 17 (30.9 %)</td>
<td>No experience with French kissing</td>
<td>N = 10 (18.2 %)</td>
<td>Experience with French kissing</td>
<td>Experience with caressing under clothes, cuddling nude</td>
<td>N = 3 (5.5 %)</td>
</tr>
<tr>
<td>7- Transportation</td>
<td>–</td>
<td>Parents or caregivers transport the adolescent/ young adult</td>
<td>N = 26 (46.4 %)</td>
<td>Parents or caregivers arrange transportation, but they do not go with them</td>
<td>Parents or caregivers arrange transportation, but they do not go with them</td>
<td>N = 7 (12.5 %)</td>
</tr>
<tr>
<td>8- Care demands</td>
<td>–</td>
<td>Parents or caregivers formulate care demands</td>
<td>N = 5 (8.9 %)</td>
<td>Parents or caregivers formulate demands together</td>
<td>Parents or caregivers, and young adult formulate demands together</td>
<td>N = 23 (41.1 %)</td>
</tr>
<tr>
<td>9- Services and aids</td>
<td>–</td>
<td>Parents or caregivers apply for services and aids</td>
<td>N = 15 (26.8 %)</td>
<td>Young person learns the procedures to apply for services and aids</td>
<td>Young person learns the procedures to apply for services and aids</td>
<td>N = 17 (30.4 %)</td>
</tr>
<tr>
<td>10- Rehabilitation services</td>
<td>–</td>
<td>Young person consulted paediatric rehabilitation care</td>
<td>N = 5 (8.9 %)</td>
<td>No consultation of rehabilitation care</td>
<td>Young person consulted adult rehabilitation services</td>
<td>N = 12 (21.4 %)</td>
</tr>
</tbody>
</table>

N, number of participants; RTP, Rotterdam Transition Profile; SD, standard deviation.
– = item does not contain the answer option "0- No experience".
understand how much autonomy is part of conversations with youths with CP. Furthermore, as no data on the reliability of the original version of the instrument were published, the present study contributes to filling a literature gap. Overall, the transition to adulthood of youths with disabilities, such as CP, may be more complex than for typically developing individuals, as several aspects related or not to the disability itself, such as skills needed for health maintenance, insufficient experience in activities, social isolation, and parental education are critical. Our results highlight that Brazilian youth with CP may need more support and develop specific strategies to achieve full autonomy in most areas assessed. However, it is worth mentioning these findings illustrate the autonomy levels of youths with CP who are able to respond to the RTP, and cannot be extended to youths with severe cognitive impairments.

In the studied population, the area of highest concern was housing, with 89.3% of participants reporting no autonomy or still acquiring autonomy to live independently. Similar unsatisfactory results were observed by Donkervoort et al., as 75% of Dutch youth with CP reported not having living autonomy. Van Gorp et al. reported that youths in their middle and late 20s with higher GMFCS levels tend to have lower independence in housing. Additionally, other factors that may negatively impact the acquisition of autonomy in housing for youth with CP include lower rates of formal employment and increased financial instability over the years.

In contrast with our findings, Dutch youths with CP have reported high levels (90%) of autonomy in transportation compared to Brazilian peers, where only 41% were autonomous. This difference may be explained by discrepancies across countries regarding accessible public transportation and safety in public places. For education, in our sample, 75% of the participants completed or were attending professional education, however, only 37.5% were involved in some form of employment. Differently, nearly 80% of youth with CP without intellectual disability in Sweden were involved in some form of employment or professional education, which suggests challenges faced by youths from low and middle-income countries.

Intimate relationships and sexuality are other potential areas of concern for youth with CP during transition to adulthood. In our results, only eight (14%) participants had a romantic relationship or partner and twice that amount (28.6%) reported not having experienced a romantic relationship yet. Regarding sexuality, 32% of the sample reported having no experience with kisses, caresses, and sexual intercourse, while 44.6% reported having experience with sexual intercourse. The results are in agreement with another study where approximately half of the youth with CP had experience with intimate relationships and 5% were currently living with a partner. These findings highlight the need for multidisciplinary teams to support youth with CP regarding this important aspect of life.

It is known that the transition of care is complex, and health services for youths with childhood-onset disabilities need to evolve. Regarding rehabilitation services, most youth with CP (69.3%) reported attending services adequate to their age. However, no information was collected about type and focus of services delivered, or the level of satisfaction of youths with the services. Recent evidence has shown
that for French youths with CP, the levels of satisfaction with motor rehabilitation have decreased from childhood to adolescence and young adulthood. Little is known about rehabilitation services provided to youth with CP around the world, especially in Brazil, thus these aspects need to be explored in future studies.

The area with the highest levels of autonomy in our sample was leisure, with 73.2% of youths reporting going out with friends. Similar results were found in Dutch and Swedish youth with CP. However, compared to adolescents in the general population, youth with CP may spend less time with friends, and their satisfaction with the frequency and type of leisure activities they attend should be explored in more detail.

As expected, age was significantly correlated with several RTP domains, indicating that participants become more autonomous as they grow older, except for housing and rehabilitation services, which may rely more on environmental factors. These results corroborate findings from longitudinal studies.

After correcting for age, autonomy in participation was significantly associated with participant and context-related factors. GMFCS and MACS levels seem to be relevant factors to the acquisition of autonomy, as individuals with lower functional levels may experience less autonomy in the areas of education and employment, finances, housing, transportation, and services and aids. Similar influence of functional levels was observed by Alriksson-Schmidt et al., as Swedish youth with CP who better functioning were more likely to live independently, and those with higher MACS and GMFCS levels needed more personal assistance in daily life. Occupational status and personal finances were also associated with MACS, with those with the mildest disabilities being more likely to be employed.

Unexpectedly, in our study, those with higher motor disability levels had higher autonomy in care demands. We hypothesize that their increased need for assistance during their development may have favored autonomy in this area. However, further research is needed to clarify this finding.

Exploring other aspects of participation, studies have highlighted context-related factors as central to understanding the participation of individuals with disabilities, which is supported by our findings. Participants’ higher educational levels were associated with higher autonomy in transportation, highlighting a possible role of education as a pathway to autonomy. In contrast, higher caregiver education was associated with decreased autonomy in finances, transportation, and sexuality. Environmental factors such as parents’ and caregivers’ characteristics are complex to understand, as aspects such as protective parenting style and parental stress may impact attendance in domestic life and relationships.

Interestingly, household income was associated with decreased autonomy in leisure activities. While the availability of resources has been reported as a facilitator for participation, families with youth with CP may have lower expectations regarding future and success compared to families with typically-developing youths. Therefore, particularities of family dynamics or attitudes may be potential barriers to the acquisition of autonomy. As participation is a complex construct, the unidimensional analysis of the factors associated with autonomy in participation used in our study may have limited our comprehension of some relevant factors, thus further investigation using more comprehensive models is warranted.

Overall, the RTP is a short and useful tool to identify autonomy in participation in key life areas that need attention during transition to adulthood. Clinicians may need to provide examples to facilitate understanding of some items, and should support respondents so they are comfortable talking about their autonomy. The availability of this instrument will support the transition planning of Brazilian youth, by highlighting their strengths and challenges, as well as potential areas for intervention. Our RTP findings point to critical areas such as relationships, sexuality, transportation, and housing. Information and support in these areas are essential to guide transition programs in Brazil.

Conclusion

The RTP Brazilian Portuguese version is cross-culturally adapted for use with the Brazilian population. RTP revealed good levels of autonomy in leisure and rehabilitation, and low levels of autonomy in housing and intimate relationships, and finances among Brazilian youth with CP. Autonomy in participation was associated with age, GMFCS, MACS, and with context-related factors, which may act as barriers or facilitators in the acquisition of autonomy.

Conflicts of interest

All authors declare that they have no competing interests.

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Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.bjpt.2024.101080.

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