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Physical activity level of schoolchildren with cystic fibrosis according to the Habitual Activity Estimation Scale (HAES)

Nível de atividade física de escolares com fibrose cística segundo o Habitual Activity Estimation Scale (HAES)

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Abstract

Background: cystic fibrosis (CF) is a multisystemic health condition that primarily affects nutritional status and the cardiorespiratory system, leading to limitations in exercise capacity and, consequently, reduces Physical Activity Levels (PAL). **Aim:** to analyze the PAL of school-aged children with CF through the application of the Habitual Activity Estimation Scale (HAES) questionnaire. **Methods:** this quantitative, descriptive and exploratory study, included scholars with CF, aged between 5 and 15 years, who were receiving outpatient care at a reference center. The HAES questionnaire was administered during outpatient visits with the children and their caregivers. Anthropometrical information was obtained from medical records, and the data were presented using descriptive statistics, utilizing the Statistical Package for the Social Sciences (SPSS®) 20.0 and Microsoft Excel®. **Results:** a total of 23 scholars participated (60.87%, male), with a mean age of 10.26 ± 3.09 years, and a mean body mass index (BMI) of 16.69 ± 2.32 kg/m^2. Analysis of inactive behavior showed an average of 2:37 hours on weekdays and 8:38 hours on weekends. **Conclusion:** the PAL of the evaluated schoolchildren with CF considered adequate according to the HAES, both on weekdays and weekends, demonstrating that the questionnaire is a viable alternative for measuring PA levels, considering the high cost and limited availability of accelerometers.

Keywords: Physical Activity; Cystic Fibrosis; Sedentary Behavior.

Resumo

Introdução: a fibrose Cística (FC) é uma condição de saúde multissistêmica que compromete principalmente aspectos nutricionais e o sistema cardiorrespiratório, os quais determinam limitação da capacidade de exercício e, consequentemente, redução dos níveis de atividade física (NAF). **Objetivo:** analisar o NAF em escolares com FC por meio da aplicação do questionário Habitual Activity Estimation Scale (HAES). **Métodos:** estudo quantitativo, descritivo e exploratório, incluiu escolares com FC, entre 5 e 15 anos, em acompanhamento ambulatorial em um centro de referência. O questionário HAES foi aplicado durante consulta ambulatorial nos indivíduos com FC e seus responsáveis. Informações antropométricas foram consultadas em prontuários e os dados obtidos foram apresentados em estatística descritiva utilizando-se o software Statistical Package for the Social Sciences (SPSS®) 20.0 e o Microsoft Excel®. **Resultados:** participaram 23 escolares (60,87% meninos), com média de idade de 10,26 ± 3,09 anos e índice de massa corporal (IMC): 16,69 ± 2,32 kg/m^2. A análise do comportamento inativo em dias da semana e nos finais de semana apresentou média de horas (h) de 2:37h e 3:16h, respectivamente, e a média de horas de comportamento ativo foi de 9:32h no dia da semana e, no final de semana, 8:38h. **Conclusão:** o NAF dos escolares com FC avaliados apresentou-se adequado de acordo com o HAES, tanto em dias de semana quanto no final de semana, demonstrando que o questionário é uma alternativa viável para mensurar o NAF, considerando o alto custo e baixa disponibilidade dos acelerômetros.

Palavras-chave: Atividade Física; Fibrose Cística; Comportamento Sedentário.

INTRODUCTION

Cystic fibrosis is a genetic disease caused by an alteration in the long arm of chromosome 7, leading to dysfunction of the Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) protein, compromising the transport of water and salt in cells and causing accumulation of mucus and dysfunction of some organs[1], with systemic clinical manifestations in affected individuals[2]. CF used to be limited to pediatric patients for its high lethality, but currently, there has been an increase in the number of individuals in the adult age group[3] for several reasons, such as the milder forms of the health condition, the presence of early diagnosis, and proper multidisciplinary monitoring[4]. In addition, new drug technologies aimed at gene therapy, such as Trikafta[5], recently included in the repertoire of the Unified Health System (SUS), reduce functional impairment, thus increasing life expectancy and quality in patients with CF[1].

Among the systemic impairments of CF, dysfunction in the respiratory system is the main cause of death in these individuals[6]. The progression of the lung condition causes symptoms such as physical tiredness and shortness of breath, which limit the ability to tolerate exercise and result in physical inactivity, directly affecting health and quality of life[6]. Thus, physical inactivity is a predictive factor for the progression of morbidity and mortality[6]. Thus, physical inactivity is a predictive factor for the progression of morbidity and mortality[7]. It is therefore of utmost importance that individuals remain physically active, whether through exercise or physical activity.

The term physical exercise refers to a structured activity with specific intensity, duration, and frequency, while physical activity encompasses daily life actions in four categories (free time, commuting, studying, and household chores)[8,9]. Both contribute to the management of the clinical condition, slowing the decline in lung function, and improving physical activity level (PAL), nutritional aspects, muscle strength, and aerobic capacity[10]. The benefits vary according to the type, frequency, and length of practice, and individuals with CF are increasingly less clinically compromised and able to perform regular physical activity and exercise[6].

It is worth pointing out that increased PAL in CF has been associated with improved physical fitness and lower mortality rates. In addition, the increase in physical activity is attributed to a decline in lung function, greater bone mineral density, and improved health-related quality of life[7]. However, compared to those without comorbidities, adults with CF spend less time doing moderate to vigorous intensity exercise and do it less often. It is no different in the pediatric age group since children are also not as active as their peers without the diagnosis[11].

In this context, various instruments are available to assess PAL in different health conditions[12]; in pediatrics, the Habitual Activity Estimation Scale (HAES) was developed given the need to determine children's PAL[13]. The instrument has been validated for children and adolescents with CF[14] aiming to assess – in a quick, easy, and effective way – the relationship between higher ALI and better prognosis. Therefore, this study aimed to analyze the ALI in schoolchildren with CF using the HAES.

METHODS

This is a quantitative, descriptive, exploratory study that included schoolchildren with a confirmed diagnosis of CF – through the sweat test and genetic examination – aged between 5 and 15 years old, under outpatient follow-up at the Joana de Gusmão Children's Hospital (HIJG), from January to September 2023. Individuals with cognitive, neurological, hearing, or visual impairment were not eligible. All minors signed an informed consent form, and their guardians signed a consent form to participate in the study. The project was approved by the Research Ethics Committee under CAEE 80800217.4.0000.5361. Figure 1 shows a flowchart of the stages involved in attracting patients for data collection.

Initially, participants were interviewed at the hospital, and data were collected on anamnesis (name, address, age, and gender), anthropometry, with height – in cm – collected using a Welmy® stadiometer, body mass – in kg – using a Wiso® digital scale, and body mass index (BMI) calculated by the Brazil Telehealth Program[15,16]. Data on the CF genotype and the presence of pathogens were gathered from medical records. HAES[14] was then applied by a team of trained researchers. Individuals up to the age of 11 answered the questionnaire with the full or partial assistance of their guardians, and those over the age of 11 answered accompanied by their parents, but without assistance in answering. All the guardians answered their specific part of the questionnaire.

HAES provides 30 questions to assess habitual PA on two days of the week over the last two weeks. These are divided into a typical weekday (TD) (Tuesday, Wednesday, or Thursday) with 15 questions, and a typical Saturday (TS) with the same 15 questions. The first eight questions concern the time the child or adolescent spent doing the tasks: "At what time did your child/adolescent get out of bed in the morning?"; "At what time did your child/adolescent start eating breakfast?"; "How long did your child/adolescent spend eating breakfast?"; "What time did your child/adolescent start eating lunch?"; "How long did your child/adolescent spend eating lunch?"; "What time did your child/adolescent start eating dinner?"; "How long did your child/adolescent spend eating dinner?"; and "What time did your child/adolescent go to bed?". This is followed by four questions regarding PAL: "Between the time you got out of bed until you started breakfast"; "After you finished breakfast until lunch"; "Between the end of lunch and the start of dinner"; and "After you finished dinner until it was time to go to bed", which

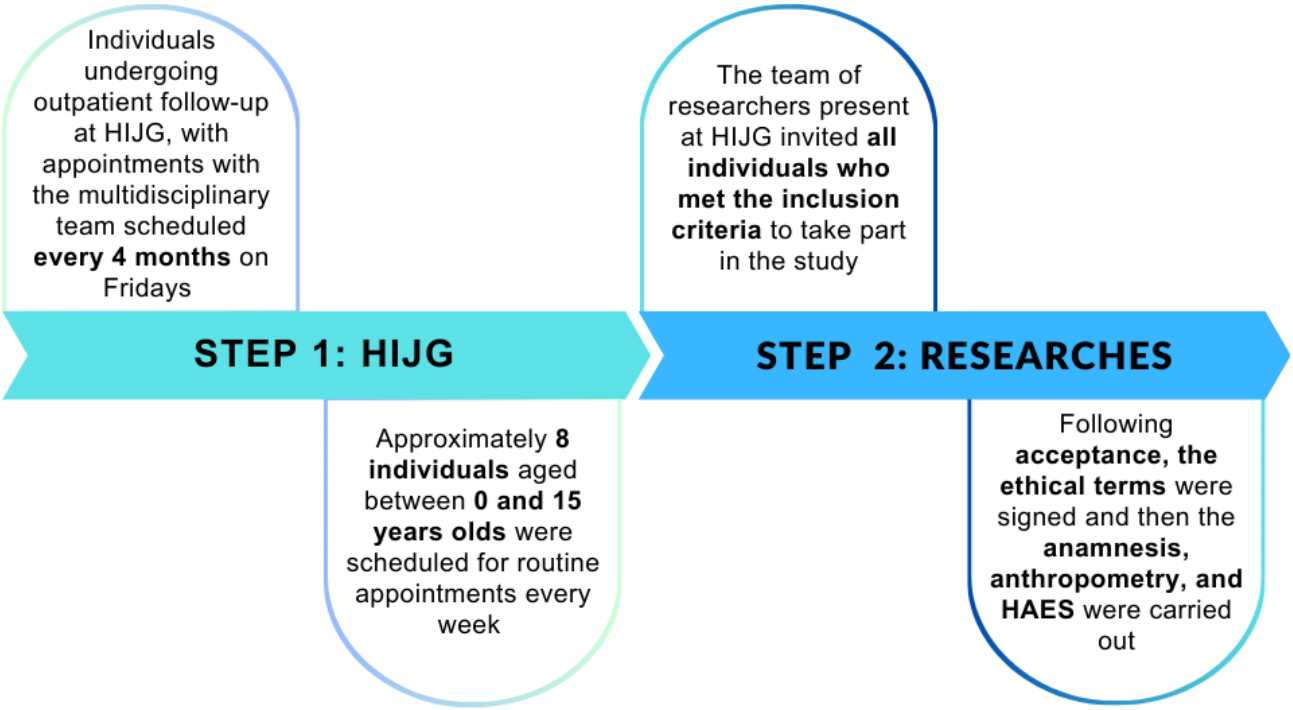

Figure 1. Flowchart for gathering patients for data collection.
Source: Developed by the authors, 2024.

should be answered in an estimate of the percentage of time the individual spent at each of the four levels: "Inactive, somewhat inactive, somewhat active, or active". Finally, three objective questions focus on the caregiver's perception of PAL[13].

The HAES items ask for times of day for certain activities, scoring as a percentage of time: a) Inactive – lying down, sleeping, resting, napping; b) Somewhat inactive – sitting, reading, watching television, playing video games, time in front of the computer, playing or practicing activities that are mainly done in a sitting position; c) Somewhat active – walking, shopping, light household chores (e.g. washing dishes); d) Active - running, jumping, cycling, skateboarding, swimming or playing games that require heavy movements and make you lose your breath, and in each section, the sum of the time spent on all activity levels must be equal to 100%.

The data collected were processed on the Statistical Package for the Social Sciences (SPSS®) 20.0 software, based on descriptive statistics, shown as absolute and relative frequencies for categorical variables, and mean and standard deviation for quantitative variables. The percentage (%) of time spent on these activities was calculated to provide the HAES results, and the data were also converted to time in hours via Microsoft Excel®. This calculation was based on the waking, eating, and sleeping times, based on the % averages. Total activity (TA) was also calculated as "somewhat active" + "active" and total inactivity (TI) as 'inactive' + "somewhat inactive" for each day[14].

RESULTS

A total of 23 schoolchildren participated in the study, with a positive diagnosis for CF usually occurring at 2 months of age according to family members' reports, with a mean age of 9.95±3.18 years and a BMI of 16.74±2.36 kg/m^2, most of whom were male (60.87%). Table 1 shows the detailed data on the characterization of the sample.

Table 2 shows the data for all the questions in the questionnaire, with the answers for the typical weekday and the typical Saturday. The results show higher TA in the TD, with 63.99% vs 57.66% in the TS. The average TA was 9:05:24 vs. 2:56:39 for IT. In addition, in terms of percentage, the results for the periods between the time the individual got out of bed and the start of breakfast show greater active time in the TD (55%) and greater inactive time in the TS (50%). In turn, after finishing breakfast until lunch, there was greater active time on both days (77.82% and 64.35%). In the period between the end of lunch and the beginning of dinner, active time was also higher on both days (84.46% and 82.17%). Finally, after finishing dinner until bedtime, inactive time was higher on both days (56.30% and 60.43%). The students evaluated were active most of the time, with a TA of 60.82%.

Figures 2 and 3 describe the PAL classification on a typical weekday and a typical Saturday, respectively. The individuals' behavior was similar when comparing the PAL classifications according to the time of day, with less active time in the morning and more active time in the afternoon. Total inactivity time on a typical day amounted to 2h and 37 min and total PA amounted to 09h and 32 min,

Table 1. Sample characterization.

Variables	Sample
Age (years)	9.95±3.18
Sex N (%)	
F	9 (39.13)
M	14 (60.87)
BMI (kg/m²)	16.74±2.36
Underweight	2 (8.70)
Eutrophic	18 (78.26)
Overweight	3 (13.04)
Genotype N (%)	
ΔF508 heterozygous	5 (21.74)
ΔF508 homozygous	10 (43.48)
Other mutations	8 (34.78)
Infection by pathogens N (%)	
Yes	23 (100)
No	0 (0)
Pathogens	
H. influenza	1 (4.35)
S. aureus	18 (78.26)
P. aeruginosa	20 (86.96)
B. cepácea	7 (30.43)
S. malt	1 (4.35)

Data are given as mean±standard deviation and percentage (). N: number of individuals; BMI: body mass index; %: percentage of predicted; Kg/m²: kilogram per square meter.

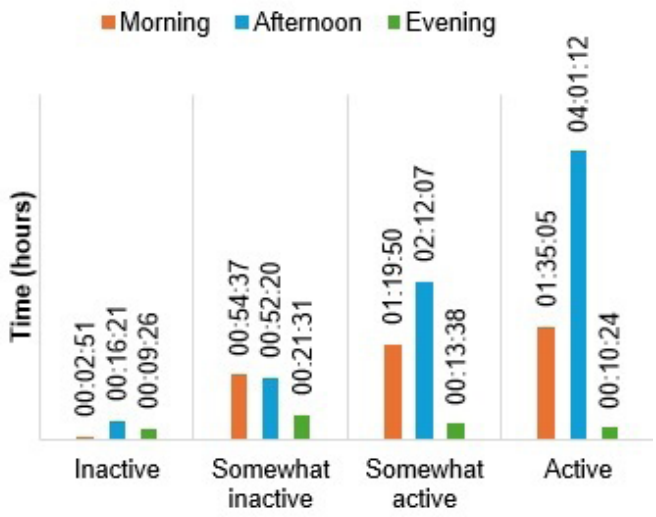

Figure 2. PAL on a typical weekday.

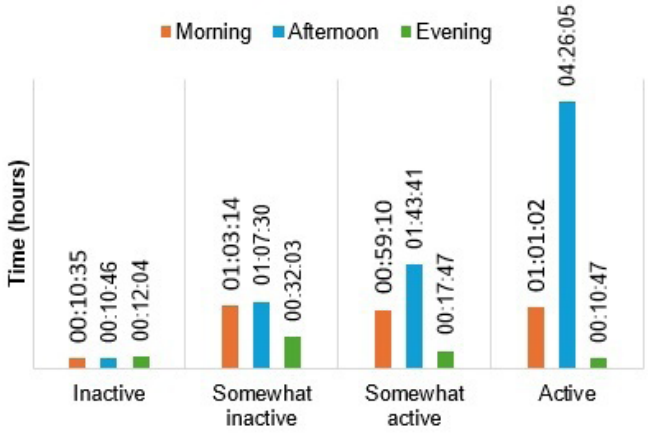

Figure 3. PAL on a typical Saturday.

while on a typical Saturday total inactivity amounted to 3h and 32 min and total PA amounted to 08h and 38 min.

Table 3 shows the results of the family member's perceptions. Regarding the participant's general level of PA, according to the family's perception of a typical day and a typical Saturday, most family members considered it to be active PA (43.48%). The guardians also reported that a typical weekday and a typical Saturday were similar (47.83% and 60.87%, respectively) to the schoolchild's day-to-day life. When asked about PAL, the reported PAL for a typical day and a typical Saturday did not change (65.22% and 56.52%, respectively) compared to the previous six-month period.

DISCUSSION

Our findings showed a similarity in the amount of time spent by the children and adolescents analyzed on PAL in a TD and a TS, with "very active" behavior predominantly in the afternoon, which may be associated with the period in which the students have access to more free activities since the morning routine involves medication and inhalation, which requires time and rest for it to take place as properly as possible. In addition, the time spent inactive was found to be longer on Saturdays, which may be because students have more time to rest since they do not have to go to school at weekends. A 2012 study showed higher PA values in the HAES in the TSs than in the DTs (median 63.2 vs. 55.7), data which corroborates our findings[17].

It is worth highlighting that the sample analyzed consisted of school-age children (mean age 9.95±3.18), a period in which sedentary activities - classes, homework, and excessive screen time - and physiotherapy, demand time, thus leading to a potential decrease in PAL. In addition, the progression of health conditions can compromise the exercise capacity and pulmonary function of individuals with CF as they get older[18], which also interferes with PAL. However, our findings show that the PAL is adequate on both days, according to the recommendations of the World Health Organization (WHO)[9,19], suggesting that neither the

Table 2. HAES characterization according to a typical weekday and a typical Saturday.

	Periods of the day	Variable	TD	TS
			Mean ± SD (min./max.)	Mean ± SD (min./max.)
MORNING	From getting up to having breakfast (%)	Inactive	12.39% ± 24.81 (0/90)	13.26% ± 26.95 (0/100)
		Somewhat inactive	35% ± 36.33 (0/100)	41.74% ± 37.61 (0/100)
		Somewhat active	29.57% ± 32.92 (0/100)	23.26% ± 26.86 (0/90)
		Active	20.43% ± 37.5 (0/100)	21.74% ± 35.5 (0/100)
	After breakfast to the beginning of lunch (%)	Inactive	0% ± 0 (0/0)	4.35% ± 11.21 (0/50)
		Somewhat inactive	22.17% ± 23.97 (0/70)	31.3% ± 31.95 (0/100)
		Somewhat active	34.78% ± 26.86 (0/100)	31.52% ± 30.57 (0/100)
		Active	43.04% ± 32.56 (0/100)	32.83% ± 37.13 (0/100)
AFTERNOON	End of lunch and beginning of dinner (%)	Inactive	3.7% ± 9.44 (0/35)	2.39% ± 6 (0/20)
		Somewhat inactive	11.84% ± 15.22 (0/50)	15% ± 19.36 (0/60)
		Somewhat active	29.89% ± 29.81 (0/100)	23.04% ± 21.25 (0/70)
		Active	54.57% ± 33.5 (0/100)	59.13% ± 36.32 (0/100)
EVENING	After dinner until going to bed (%)	Inactive	17.17% ± 30.1 (0/100)	16.52% ± 23.85 (0/90)
		Somewhat inactive	39.13% ± 32.56 (0/100)	43.91% ± 33.91 (0/100)
		Somewhat active	24.78% ± 24.33 (0/100)	24.35% ± 23.27 (0/80)
		Active	18.91% ± 33.23 (0/100)	14.78% ± 29.52 (0/100)
	Task completion time (h)	Got up	07:50h ± 1:20 (05:40/10:00)	08:48h ± 1:11 (06:00/10:30)
		Breakfast	08:13h ± 1:19 (06:00/10:20)	09:12h ± 1:10 (06:30/10:45)
		Breakfast Time	00:20m ± 0:12 (00:05/01:00)	00:19m ± 0:09 (00:00/00:40)
		Lunch	12:03h ± 0:20 (11:00/12:30)	12:21h ± 0:30 (11:30/13:30)
		Lunch Time	00:25m ± 0:13 (00:10/01:00)	00:23m ± 0:07 (00:15/00:40)
		Dinner	19:50h ± 0:51 (17:30/21:30)	20:14h ± 1:07 (17:00/22:00)
		Dinner Time	00:24m ± 0:09 (00:10/00:45)	00:21m ± 0:07 (00:10/00:40)
		Went to bed	21:09h ± 4:22 (20:00/01:20)	21:48h ± 4:46 (20:30/00:30)

TD: typical weekday (Tuesday, Wednesday, or Thursday); TS: typical Saturday; SD: standard deviation; m: minutes; min.: minimum; max.: maximum; %: percentage; h: hours.

Table 3. Relative's perception of the schoolchild with CF.

Perception	Variables	Typical day	Typical Saturday
		N (%)	N (%)
Schoolchild's general level of PA	Very inactive	0 (0)	0 (0)
	Inactive	1 (4.35)	0 (0)
	Somewhat inactive	0 (0)	1 (4.35)
	Somewhat active	1 (4.35)	4 (17.39)
	Active	11 (47.83)	10 (43.48)
	Very active	10 (43.48)	8 (34.78)
Weekday experience compared to what was described	Very similar	11 (47.83)	14 (60.87)
	Similar	9 (39.13)	7 (30.43)
	Slightly different	2 (8.70)	0 (0)
	Very different	1 (4.35)	2 (8.70)
In the last 6 months, considering the schoolchild's PAL compared to before	Much less active	0 (0)	0 (0)
	Somewhat less active	3 (13.04)	4 (17.39)
	Remained the same	15 (65.22)	13 (56.52)
	Somewhat more active	3 (13.04)	4 (17.39)
	Much more active	2 (8.70)	2 (8.70)

PA: physical activity; PAL: physical activity level; %: percentage.

usual behavior of the age group nor the diagnosis of CF compromised the active time of the sample studied.

Furthermore, based on the premise that the "somewhat active" option in the HAES (walking, shopping, and light household chores) refers to activities of moderate intensity[9] and that "active" (running, jumping, skipping, cycling, skateboarding, swimming, or playing games) refers to activities that require intense movement and effort – and can therefore be considered vigorous intensity[9] – the daily value recommended by the WHO for PA was achieved by the sample investigated. The WHO establishes a minimum of 60 minutes/day of activity and 3 days a week, with moderate-intensity aerobic exercise and muscle strengthening, for children and young people aged 6 to 17. For children aged 3 to 5, at least 3 hours a day of PA of any intensity is recommended, with at least

1 hour of moderate to vigorous intensity as the ideal level for maintaining an active life[9,19]. In this study, this time was reached, but the frequency of at least 3 days, the type of PA, and the intensity could not be identified given the nature of the instrument used, which only assesses two days of the week, thus constituting a limitation.

There is a consensus that any PA is more beneficial than none[9], making this information key to the effective management of chronic conditions, especially CF[7]. Accordingly, a systematic review[6] shows that interventions involving regular exercise in CF - for six months or more - are likely to improve exercise capacity, compared to no training at all. These PE interventions range from varied muscle-strengthening training to aerobic training. Decreased symptoms of anxiety and depression and increased health-related quality of life appear to be further benefits associated with regular PA in CF[20]. In addition to PA, it is worth noting that PE has several positive effects, such as relieving dyspnea, improving exercise tolerance[21], maintaining lung function, clearing sputum (by combining hyperventilation, mechanical vibration, and coughing, which affect changes in sputum rheology), and optimizing expectoration[22,23]. Therefore, practices like this should be encouraged by the multi-professional team at referral treatment centers.

Specifically, exercise programs using video games with active games (running, dancing, boxing) can also reach moderate intensity and can increase cardiorespiratory responses up to the level of intensity recommended for aerobic training[24]. In addition, studies have supported the hypothesis that exercise programs involving active video games can increase adherence to treatment[25] since these games appear to provide more personal satisfaction than conventional exercise programs. Thus, it emerges as an alternative to change a sedentary lifestyle in CF, and in a long-term fashion, which can lead to changes in PAL, improving the health and quality of life of those who practice it[1].

In short, PAL in individuals with chronic respiratory disease, such as CF, has little effect on lung function but improves exercise tolerance[6]. Therefore, the search for PA in daily tasks and the practice of PE in reference centers for treatment should be encouraged from the earliest years of life, as this habit can lead to a better quality of life for schoolchildren until adulthood, given the benefits of a non-sedentary life[10,19].

Although validated PA questionnaires and logs are subjective measures, they have been widely used to measure PAL in children and adolescents[7,14,26-34]. These tools are often used for their low cost, easy access, and applicability in research[35], despite the acknowledged risk of bias with this method, since there may be a failure of memory in the answers and an overestimation of time in terms of exercise practice. It is worth noting that the accelerometer is the gold standard instrument for measuring PAL, which provides a record of PA – every minute – objectively verifying active and inactive time[36]. Studies evaluating PAL with accelerometers in CF are lacking given their cost and availability, despite their recognized superiority in terms of validity and reliability compared to questionnaires[35]. Thus, the application of the HAES, especially if associated with the accelerometer, is considered valid for assessing PAL[14].

In this context, this study shows that the HAES questionnaire – specific for CF – is an easily applicable alternative for assessing PAL in affected children and adolescents since access to the accelerometer is not available in reference centers for treatment in the country. The data from the questionnaire can be analyzed easily and quickly and can provide immediate feedback to patients and their families, enabling a better understanding of the prognosis of individuals with CF, thereby suggesting multidisciplinary interventions to promote healthier lifestyle habits in this population.

The limitations of this study include the small sample and the presence of memory bias when answering the questionnaire. Along these lines, the use of objective instruments – such as accelerometers – combined with subjective questionnaires should be encouraged to better assess PAL in further research. The clinical relevance of the study also highlights that the HAES facilitates the monitoring of PAL in schoolchildren with CF, as its information allows for identifying sedentary behavior in individuals, which enables actions for health promotion, guidelines for practicing PA according to individual needs, and discussions between the multidisciplinary team of reference centers regarding the appropriate management of this population.

CONCLUSION

The PAL of schoolchildren with CF was adequate both on weekdays and at weekends. The use of the HAES questionnaire, specific to the CF population, proved to be a viable alternative for measuring PAL, given that the use of accelerometers is still limited in reference centers due to their high cost and low availability.

FUNDING

Nothing to declare.

CONFLICT OF INTEREST

Nothing to declare.

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