Physical activity assessment in cystic fibrosis: A position statement


Published in:
Journal of Cystic Fibrosis

Document Version:
Publisher's PDF, also known as Version of record

Queen's University Belfast - Research Portal:
Link to publication record in Queen's University Belfast Research Portal

Publisher rights
© 2015 The Authors. Published by Elsevier B.V. on behalf of European Cystic Fibrosis Society. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/), which permits distribution and reproduction for non-commercial purposes, provided the author and source are cited.

General rights
Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy
The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact openaccess@qub.ac.uk.
Physical activity assessment in cystic fibrosis: A position statement

Judy Bradley¹,²,⁎, Brenda O’Neill¹, Lisa Kent¹,², Erik H.J. Hulzebos³, Bert Arets⁴, Helge Hebestreit⁵, On behalf of the Exercise Working Group European CF Society,
for publication in Journal of CF


¹ Centre for Health and Rehabilitation Technology (CHaRT), Institute of Nursing and Health Research, Ulster University, Northern Ireland BT37 0QB, United Kingdom
² Northern Ireland Clinical Research Network: Respiratory Health, Belfast Health and Social Care Trust, Belfast, United Kingdom
³ Child Development & Exercise Center, Wilhelmina Children’s Hospital, University Medical Center Utrecht, Utrecht, The Netherlands
⁴ Department of Pediatric Pulmonology, Wilhelmina Children’s Hospital, University Medical Center Utrecht, The Netherlands
⁵ University Children’s Hospital, Würzburg, Germany

Received 26 November 2014; revised 5 May 2015; accepted 28 May 2015
Available online 26 July 2015

Abstract

Background: The aim of this position statement was to inform the choice of physical activity tools for use within CF research and clinical settings. Methods: A systematic review of physical activity tools to explore evidence for reliability, validity, and responsiveness. Narrative answers to “four key questions” on motion sensors, questionnaires and diaries were drafted by the core writing team and then discussed at the Exercise Working Group in ECFS Lisbon 2013. Results and summary: Our current position is that activity monitors such as SenseWear or ActiGraph offer informed choices to facilitate a comprehensive assessment of physical activity, and should as a minimum report on dimensions of physical activity including energy expenditure, step count and time spent in different intensities and sedentary time. The DigiWalker pedometer offers an informed choice of a comparatively inexpensive method of obtaining some measurement of physical activity. The HAES represents an informed choice of questionnaire to assess physical activity. There is insufficient data to recommend the use of one diary over another. Future research should focus on providing additional evidence of clinimetric properties of these and new physical activity assessment tools, as well as further exploring the added value of physical activity assessment in CF.

© 2015 The Authors. Published by Elsevier B.V. on behalf of European Cystic Fibrosis Society. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

Keywords: Physical activity assessment; Position statement

⁎ Corresponding author.
E-mail addresses: jm.bradley@ulster.ac.uk (J. Bradley), b.onNeill@ulster.ac.uk (B. O’Neill), lisa.kent@belfasttrust.hscni.net (L. Kent).

http://dx.doi.org/10.1016/j.jcf.2015.05.011
1569-1993 © 2015 The Authors. Published by Elsevier B.V. on behalf of European Cystic Fibrosis Society. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).
The aim of this position statement was to inform the choice of physical activity tools for use within CF research and clinical settings to facilitate physical activity measurement.

1. Methods

To achieve this aim, it was agreed that two parallel strands of work would be conducted:

1.1. Strand 1

Strand 1 consisted of a systematic review of the clinimetric properties (reliability, validity, and responsiveness) of physical activity tools using methods adopted from ECFS Research in Nursing and Allied Health Professions Working Group and ECFS Clinical Trials Network [16,17].

Studies on paediatric (≤12 yrs), adolescent (13–17 yrs) and adult populations (≥18 yrs) in CF were targeted. The search was performed from inception of the databases to December 2013. A systematic search of the following databases was undertaken: MEDLINE, EMBASE and PubMed using relevant search terms e.g. cystic fibrosis AND activity OR habitual activity OR questionnaires OR motions sensors OR diaries.

A range of specific motion sensors, questionnaires and diaries were also searched for, these included commonly used tools and also all tools identified in the survey (more details in the online supplementary data). “In house” questionnaires and diaries (i.e. no published questionnaire or diary could be sourced) were excluded from the systematic review.

Reference lists of review articles were also reviewed to identify any additional studies. Data that provided evidence of clinimetric properties (reliability, validity, and responsiveness) of physical activity motion sensors, questionnaires and diaries are summarised in Tables 1 and 2 (full data tables are presented in the online supplementary data). We also explored the relationship between each physical activity motion sensor, questionnaire/diary, and outcome measures used in clinical practice and research.
<table>
<thead>
<tr>
<th>Motion Sensor</th>
<th>Reliability</th>
<th>Convergent Validity</th>
<th>Discriminate Validity</th>
<th>Correlation with other outcomes</th>
<th>Responsiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>RT3 (plus TriTrac, earlier version of RT3)</td>
<td>None</td>
<td>None</td>
<td>[26]</td>
<td>None</td>
<td>TriTrac—evidence of responsiveness to IVAB * b, c [27]</td>
</tr>
<tr>
<td>Caltrac</td>
<td>Reliable over 3 points in time * b, c [28]</td>
<td>Evidence of correlation with the LSI monitor * b, c [28]</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Large Scale Integrated Motor Activity Monitor: LSI e-AR</td>
<td>Reliable over 3 points in time * b, c [28]</td>
<td>Evidence of correlation with Caltrac monitor * b, c [28]</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>DigiWalker</td>
<td>None</td>
<td>Evidence of correlation with SenseWear * [18]</td>
<td>None</td>
<td>None</td>
<td>Evidence of responsiveness to IVAB * b, c [29]</td>
</tr>
</tbody>
</table>

* Adults.
* Adolescents.
* Children.
<table>
<thead>
<tr>
<th>Study</th>
<th>Reliability</th>
<th>Convergent validity</th>
<th>Discriminate validity</th>
<th>Correlation with other outcomes</th>
<th>Responsiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Habitual Activity Estimation Scale (HAES)</td>
<td>Reliable over two points in time a, b, c [25]</td>
<td>Evidence of correlation with activity monitors (Sensewear and Actigraph) a, b, c and diaries (Boucher and Bratteby) a, b, c</td>
<td>Within CF able to discriminate between responders and non-responders to an exercise programme b, c [31]</td>
<td>Significant correlation with exercise capacity, body mass and lung function b, c [9,10,30]</td>
<td>Evidence of responsiveness to training programmes b, c [11,31]</td>
</tr>
<tr>
<td>Baecke Questionnaire</td>
<td>None</td>
<td>None</td>
<td>Evidence of significant correlation with bone mineral density and energy intake a [32,33]</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Kriska Modifiable Activity Questionnaire</td>
<td>Reliable over three points in time b, c [28]</td>
<td>Evidence of correlation with activity monitor (Caltrac, LSI) b, c and with physical activity questionnaire (Harvard Alumni) b, c [28]</td>
<td>Able to discriminate between CF vs healthy b, c [34]</td>
<td>Significant correlation with exercise capacity and lung function b, c [34]</td>
<td>None</td>
</tr>
<tr>
<td>Physical Activity Status Questionnaire (PAS-Q)</td>
<td>None</td>
<td>None</td>
<td>Able to discriminate between CF and healthy a Within CF able to discriminate between different fat free mass, different lung function a [35–37]</td>
<td>Evidence of significant correlation between lung function a and bone mineral density a b [35,36,38]</td>
<td>None</td>
</tr>
<tr>
<td>Harvard Alumni Survey</td>
<td>Evidence of reliability over 3 time points c [28]</td>
<td>Evidence of correlation with activity monitors (Caltrac) b, c and with physical activity questionnaires (Kriska Modifiable Activity Questionnaire) b, c [28]</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Physical Activity Questionnaire for Children (PAQ-C)</td>
<td>None</td>
<td>None</td>
<td>Able to discriminate between CF and healthy c [39]</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Lipid Research Clinics Questionnaire (LRC)</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>Evidence of significant correlation with exercise capacity a b [24]</td>
<td>None</td>
</tr>
<tr>
<td>7-Day Physical Activity Recall (Interview) (7-Day PAR/Five City Project)</td>
<td>None</td>
<td>Evidence of correlation (Actigraph) a, b, c [24]</td>
<td>None</td>
<td>Evidence of significant correlation with bone mineral density and with urinary Pyridinium Crosslinks a [40]</td>
<td>None</td>
</tr>
<tr>
<td>30-day Physical Activity Recall (Interview) (30-Day PAR) International Physical Activity Questionnaire (IPAQ)</td>
<td>None</td>
<td>None</td>
<td>Within CF able to discriminate between gender b [41]</td>
<td>Significant correlation with exercise capacity b [41]</td>
<td>Evidence of responsiveness to training programme b [41]</td>
</tr>
<tr>
<td>Bouchard Diary</td>
<td>None</td>
<td>Evidence of correlation with HAES b, c [9]</td>
<td>Able to discriminate between CF and healthy a [42]</td>
<td>Evidence of significant correlation with lung function a [42]</td>
<td>None</td>
</tr>
<tr>
<td>Bratteby Diary</td>
<td>Reliable over two points in time a, b, c [25]</td>
<td>Evidence of correlation with activity monitors (Actigraph) a, b, c and physical activity questionnaires (HAES) a, b, c [25]</td>
<td>Able to discriminate between CF PI and PS b [15]</td>
<td>Evidence of significant correlation with exercise capacity, quality of wellbeing and body mass percentile a, b [15]</td>
<td>None</td>
</tr>
</tbody>
</table>

a Adults.  
b Adolescents.  
c Children.
1.1.2. Strand 2

In strand 2 narrative answers to “four key questions” on the use of motion sensors, questionnaires and diaries in research and clinical practice were drafted by the core writing team and then discussed at the Exercise Working Group in ECFS Lisbon 2013. Following feedback from the Exercise Working Group the answers were revised and finalised:

1. Do motion sensors/questionnaires/diaries have the potential to be used within clinical practice?
2. Do motion sensors/questionnaires/diaries have the potential to be used as an outcome measure in research?
3. What output should be reported from motion sensors, questionnaires and diaries?
4. What is an important treatment effect for motion sensors, questionnaires and diaries?

A draft manuscript summarising the results of Strand 1 and 2 was circulated to the exercise working group for review and revised until group consensus was achieved. Subsequently, the manuscript was reviewed by the ECFS Board.

1.2. Results

1.2.1. Strand 1

Data extracted as part of this review included dimensions of physical activity i.e. step counts, time spent being physically active (often broken down into different intensities and different time periods) and energy expenditure. The clinimetric properties of physical activity assessment tools have not been evaluated consistently between studies in CF. This makes it difficult to compare tools or combine the results of different studies.

1.3. Motion sensors

A summary of the clinimetric properties of motion sensors used in CF is presented in Table 1 and full data tables are presented in the online supplementary data. A larger proportion of motion sensor data is available in adults with CF compared to adolescents and children. There was a general lack of consistency between physical activity assessed by motion sensors compared to questionnaires/diaries.

The SenseWear, ActiGraph and DigiWalker have the most data supporting their clinimetric properties. Of these three only the Actigraph has data on reliability. Generally for the SenseWear and ActiGraph monitors, there is evidence of convergent validity, i.e. correlation between these monitors and other physical activity tools; and there is evidence of discriminate validity, i.e. these monitors are able to discriminate between groups that are known to differ, including CF versus healthy, between groups of people with CF with different phenotypes or stable vs unstable states. There has been exploration of the relationships between physical activity with the SenseWear ActiGraph, and DigiWalker and other clinical outcome measures in CF. There is some evidence indicating a positive correlation between physical activity and measures of lung function, exercise capacity, respiratory symptoms and bone mineral density. The SenseWear, ActiGraph and DigiWalker have data demonstrating responsiveness.

1.4. Questionnaires/diaries

A summary of the clinimetric properties of physical activity questionnaires and diaries used in CF is presented in Table 2 and ECFS website. Some studies did not provide sufficient detail about the assessment tools evaluated (e.g. in-house questionnaires) and these studies were excluded. For many of the questionnaires, information has been converted into estimates of energy expenditure (e.g. kilocalories, METs) or some other summary measure that can be used to categorise participants by their physical activity level. There was a general lack of consistency between different questionnaires/diaries and between questionnaires and monitors or diaries.

With regard to the clinimetric properties of questionnaires, the HAES has the most available data. It has data on reliability. There is evidence of convergent validity, i.e. correlation between the HAES and activity monitors and diaries. And there is evidence of discriminate validity, i.e. the HAES is able to discriminate between groups of people with CF (responders as and non responders to an exercise programme) There is some evidence indicating a positive correlation between the HAES and measures of lung function, exercise capacity, and body mass. The HAES has data demonstrating responsiveness.

There are only two diaries, the Bouchard and the Bratteby, each with some evidence of some clinimetric properties.

1.4.1. Strand 2

Narrative answers to the “four key questions” on motion sensors, questionnaires and diaries were collated and are summarised below.

1. Potential to use motion sensors, questionnaires and diaries within clinical practice. Motion sensors, questionnaires and diaries have the potential to be used within clinical practice; however there are some specific considerations for each tool. Motion sensors. An important consideration for the choice of physical activity monitor should be the purpose for which the data will be used. Whilst sophisticated activity monitors eliminate the problems of subjective assessment of physical activity (such as poor memory and biased self-reporting), they are more costly and analysis of data output can be a time burden for patients and staff. Technical skills are required to analyse and interpret the data; and use the data appropriately to individualise physical activity advice and monitor change. Future versions of the monitors and software may improve the feasibility of incorporation of motion sensors into busy clinics. Additionally many of the systems do not give direct user feedback on current activity levels which might be important for motivation. Pedometers offer a less costly alternative but usually do not facilitate in-depth assessment of activity patterns. Often simple step count may be sufficient for assessing baseline levels of activity, monitoring change and may also serve as a motivational tool.

Questionnaires. It is important to consider that questionnaires measure the perception of individual physical activity, or a caregiver-reported child’s physical activity; however they do not measure the ability of the person to be physical active, or
their perceptions of symptoms during physical activity. Questionnaires are also useful as a screening tool to identify those that may require advice about physical activity and facilitate discussion on physical activity patterns and goal setting. The use of electronic scoring systems facilitates scoring and interpretation. Questionnaires can be influenced by many other factors and do not always relate accurately to objective physical activity assessment. It is also not possible to use questionnaires to provide detailed information on physical activity levels or detect differences within individual patients over time.

Diaries. Their use is likely to be focused on facilitating discussion of physical activity patterns, to facilitate self-monitoring, explore adherence, as an aide-mémoire, as a motivational tool, and goal setting. Where possible, a standardised diary should be used in preference to an in-house diary. Diaries can be influenced by many other factors: particularly inaccurate completion and do not always relate accurately to objective physical activity assessment. It is also not possible to use diaries to provide detailed information on physical activity levels or detect differences within individual patients over time.

2. Potential to use motion sensors questionnaires and diaries as outcome measures in research

Motion sensors. Motion sensors have the potential to be used in epidemiological research and as primary endpoints in studies investigating the efficacy of exercise/physical activity interventions in CF. More research may need to be conducted in CF to explore the relationship between physical activity and true clinical endpoints (i.e. how the patient feels, functions or survives and detection of a tangible benefit for the patient). Establishing this link would raise the profile of physical activity as an outcome measure in other therapeutic trials. The use of motion sensors in multicenter clinical trials would be facilitated by efforts towards standardisation (e.g. agreement on most important physical activity dimensions, standard operating procedures for performance of the measurement and methods of analysis; training; central quality control and over reading). It is also important to achieve consensus on how to report output from motion sensors in terms of both units and cut-off categories.

Questionnaires. Questionnaires have the potential to be used in epidemiological research. As they have high variability they are more suited to being secondary endpoints rather than primary endpoints in studies investigating the efficacy of exercise/physical activity interventions in CF. For all the above dimensions there is no clear consensus on what represents an important treatment effect or the likely timeframe for change to occur. Available studies have not yet established an important clinical difference in physical activity more information on reliability and responsiveness is needed.

Diaries. We do not recommend the use of diaries as primary or secondary endpoints in studies investigating the efficacy of exercise/physical activity interventions in CF. However, they may prove to be beneficial in exploring motivation, and adherence to the prescribed intervention.
tools used within CF research and clinical settings to facilitate physical activity measurement. There are several options for both objective and subjective assessment of physical activity, and the current position of the Exercise Working Group relating to physical activity assessment is summarised below:

Motion sensors
- The activity monitor devices with the most available data are SenseWear and ActiGraph. The SenseWear and ActiGraph represent informed choices for activity monitoring in CF. This would be in agreement with the recommendations of the PRO-ACTIVE consortium [45].
- For activity monitors output relating to physical activity dimensions including energy expenditure, step count and time spent in different intensities including sedentary time should be considered in order to provide a comprehensive assessment of physical activity.
- The pedometer with the most available data in CF is the DigiWalker. The DigiWalker currently represents the most informed choice for a pedometer as there is some information on the clinimetric properties.

Questionnaires
- The questionnaire with the most available data was the HAES. The HAES currently represents an informed choice to measure physical activity via questionnaire.
- Questionnaires are useful to screen physical activity levels and generate discussion on physical activity patterns.
- Questionnaires should not be used as primary outcome measures without fully assessing their clinimetric properties. They may be useful as a secondary outcome measure or in larger epidemiological studies.

Diaries
- There is insufficient data to recommend the use of one diary over another. Diaries are useful to screen physical activity levels and generate discussion on physical activity patterns.

3. Future research

The Exercise Working Group agreed on priority areas for future research for physical activity assessment in CF. There is a need to explore the clinimetric properties of current and new technologies for the assessment of physical activity across the age range and the disease trajectory in CF. Clinimetric properties can differ depending on the population being studied and it is impossible to extrapolate findings from one group of patients to another. It is also important that when substantially different versions of existing models of motion sensors or software are available that research is conducted into their clinimetric properties. Bridging studies are also required to establish physical activity measurement as a surrogate of treatment effects. Agreement on the optimal methods of reporting objective physical activity data (i.e. which dimensions and units) and cut-offs for categorising physical activity intensity and daily step counts in CF are needed. The CF community could refer to the methodology of other initiatives such as the COMET (Core Outcome Measures in Effectiveness Trials) initiative to facilitate development of “core outcome sets” which could then be reported as a minimum in all research on physical activity in CF, making it easier to compare or combine results. Finally the link between physical activity and exercise capacity in CF needs to be further explored.

Acknowledgement

This paper is an output of the ECFS Exercise Working Group which was funded by the ECFS.

Appendix A. Supplementary data

Supplementary data to this article can be found online at http://dx.doi.org/10.1016/j.jcf.2015.05.011.

References


