RaceRunning: improving health and wellbeing in people with cerebral palsy

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Mrs Dawn Pickering (Cardiff University)
Mr Rob Henshaw (Quest88 Ltd)
Session overview

• Race-runners (RR’s) / running-bikes (RB’s)
• Impact of RR’s on health
• Impact of RR’s on wellbeing
• Practical demo (how to set up a RR)
• Q & A
Race runners / running-bikes

- 3 wheeled frame with handlebars, saddle and thoracic support
  - Propelled forward by feet
  - Various postural support accessories
- For individuals with mobility/balance disorders
- Developed in Denmark in 1989
  - Connie Hansen (OT & Paralympian)
Race runners / running-bikes

- Initial construction 1989

- and now .... www.racerunning.org
  - International disability sport (events 40m – 5000m)
  - 2011 introduced to International Wheelchair & Amputee Federation Games (IWAS)
  - 2012 included in 1st European Paralympic Youth Games
  - 2014 formal negotiations between IPC and CPISRA/Race Running
  - Active race running in 15 countries
    - CP Sport running taster days
Race runners / running-bikes

- Sport
- Therapy
- Daily living
Accessories for therapy sessions

- Pliable body support with belt
- Sheep skin cover
- Leg separator plate
Extra padding / accessories used during therapy sessions
Can running bikes be used to improve health & wellbeing?
Research on RR’s/RB’s

• Very limited published literature
    • Metabolic responses to sustained exercise/CP ISRA classes
      \((n=9\) athletes CP1 to CP6)
    • Feasibility study, \(n=50\) children with differing diagnoses
      (included GMFCS levels III & IV)
  – Bryant et al 2015) - UK
    • Pilot study, \(n=15\) children with CP (GMFCS levels IV & V)
Background

• During childhood weight-bearing activities are required to stimulate the normal development of bone

• Children with cerebral palsy (particularly non-ambulant) have reduced bone density and increased risk of fracture

• Evidence shown positive effect of weight bearing exercise on lower limb bone health in ‘typically’ developing children

• Limited evidence on effect of exercise on bone health in non-ambulant children with cerebral palsy
Modes of exercise

- Limited opportunity to exercise for non-ambulant children with CP
  - Activities at school
    - Stretching
    - Trikes (adapted)
    - Swimming
    - Horse riding
  - ‘Walkers’ are often bulky, heavy to manoeuvre
- Lessons learnt from earlier exercise interventions
  - Need for fun/enjoyable opportunities to enhance participation, fitness & improve bone strength
Pilot study

• To investigate if running bikes are a feasible and enjoyable mode of weight-bearing exercise for non-ambulant children with CP (GMFCS levels IV & V)

  – 12 week intervention
    • 3 x week; school based
  – Outcome measures
    • Week 0 and repeated Week 12
Outcome measures

• Ability to use the running bikes
• Feedback from the users
• Standing ability (GMFM-88D)
• Ultrasound bone densitometer
Participants

• Recruitment
  – Target n=12; actual n=15
  – Two specialist schools

• Participants
  – Age range 4-12 years (mean 8.4)
  – GMFCS levels (level IV = 10; level V = 5)
  – 7 boys, 8 girls
Results

Ability to use the running bikes

- **Baseline**: Unable to initiate walking with assistance (30%), Able to walk without assistance (10%), Able to run with assistance (0%), Able to run without assistance (0%)
- **Mid trial**: Unable to initiate walking with assistance (40%), Able to walk without assistance (20%), Able to run with assistance (10%), Able to run without assistance (0%)
- **End trial**: Unable to initiate walking with assistance (50%), Able to walk without assistance (30%), Able to run with assistance (20%), Able to run without assistance (0%)

*p = 0.000*
Running bike use
GMFCS level IV = Self mobility with limitations
Running bike use
GMFCS level V = Transported in a wheelchair

Week 1

Week 12
Qualitative feedback

• Physiotherapists
  • “They were really fun for the children”
  • “They could go really fast, and it was something they had never been able to do”
  • “For some it was the first time they have been able to completely move independently”

• Children
  • “It was really fun” “Happy” “Excited”
  • “I got hot!”
Results

Ultrasound bone data

Bone quality index (BQI score)

Week 0     Week 12

Left limb   Right limb

*p=0.037  p=0.075
Results

• Standing ability (GMFM-88D)

13 tasks include:-
1. Stands - arms free for 3 seconds
2. Stands - holding onto large bench with one hand, lifts 1 foot for 3 seconds

Scoring for each task:-
(0 = does not initiate, 1 = initiates, 2 = partially completes, 3 = completes)

• Showed signs of improvement (non significant)
  – Number of tasks attempted increased
Discussion

• Running bikes are fun and exciting for non-ambulant children with cerebral palsy
• Twelve week running bike use demonstrated positive health benefits
• Further research required

This study was funded by Sparks, the children’s medical research charity
RaceRunning: improving wellbeing in people with cerebral palsy.

Dawn Pickering, Physiotherapist, PhD student, Cardiff University
Well Being

• World Health Organisation, 2014
• NICE guidelines 2013
• Feeling valued as a person- subjectively experienced, realising own potential.

Emotional- happy and confident
Psychological- autonomous, resilient
Social – good relationships
RaceRunning Dragons, Cardiff

Race-Running
Sport in Movement

Join us at Wales' first Race-Running Club

Activity that's new, fun, friendly and has amazing benefits

What is it?
Learning to walk, sit and race with the support of a three-wheeled frame

Who is it for?
Anyone who has difficulties with movement, balance and walking, but is allowed to bear weight

When?
Friday night is Race-Running night - We meet 5-7pm (dinner time only)

Where?
Cardiff International Sports Stadium
Lockwith Road, Cardiff CF11 9AZ

How much?
Under 16s £1.00; Over 16s £3.00

How to support us?
Each race runner costs £1.00 - Can you help fund or make a donation?
We need volunteers to help out at our club each Friday and allow us to grow from our numbers.
Can you help with transport to events?

Our Phone: 07803 770 962
Our Email: gabriela.todd@yahoo.co.uk

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About our Club

Cardiff RaceRunning Dragons - The Welsh club for people with disabilities who want to run. We want to make running accessible and enjoyable for all.

We run from the Cardiff International Sports Stadium on Friday nights, 5-7pm (dinner time only).

Our aim is to provide a fun, friendly atmosphere where everyone is welcome.

We encourage people with disabilities to participate in running activities and to enjoy the benefits of regular exercise.

We also offer support to people who have been injured or have mobility issues.

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Kitty alive and ready to go

Team Sport Cardiff Dragons with some of their supporters on Club Night

Kitty takes off

Camera and Anthony's ready for the action

2 3 4 5 6 7 8
Moondance foundation - Cardiff Club - 8 RaceRunners
Racing
Community activity
‘I was introduced to a cerebral palsy specific sport called RaceRunning...it was just so freeing....it was just amazing!........ My activities were very short and staggered, I would never really raise my heart rate or get into an easy motor pattern. .... Gravity and my CP is what made my walking pattern so disjointed- the need to stay upright against gravity with muscles which co-contract at the faintest hint that I might fall. So at first the RaceRunner gave me the experience of what walking must be like without cerebral palsy- using motor patterns which come naturally and easily......
Katie

….So it's so beautiful on the track, fresh air, you get to obviously run on the RaceRunner ....and you can switch off that part of your brain. I think motor function just uses more - because we've got less maybe - we've got damaged brains so the bits that are alive are working 100 fold more than they're meant to, it might be the fact that somehow they can switch off and you can start thinking. What I can't do is think coherently when I walk, but I can when I Race Run...
Carry over into other activities

…it created new abilities within me not necessarily physical...I had more self confidence and more ability to deal with stressful moments in my life...I actually applied for the student president of the faculty...I was so much more happy within myself...

Race Running is safe, you do need padded shorts and a padded saddle....you don’t have to concentrate you just see the world go by.... it enabled me to stop hiding what I can’t do and say look at what I can do!.....
Race Running- parental view

‘We have found that Imogen's enthusiasm for physical activities like Race Running has enabled me and my husband to get fitter, it also helps her to sleep better.’
‘Hands on’ time!

• Demo / how to set up the RR’s for different users
• Have a go!
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Dawn Pickering  pickeringdm@cf.ac.uk
Rob Henshaw  Robert.Henshaw@quest88.com