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Objective Physical Activity Measurement for a Child With Special Health Care Needs

Heather Aldrich PhD[a,*], Catherine Jankowski PhD, FACSM[a], Kate Lyden PhD[b], Bonnie Gance-Cleveland PhD, RNC, PNP, FAAN[a]

[a]*College of Nursing, University of Colorado Anschutz Medical Campus, Aurora, CO*
[b]*School of Medicine, University of Colorado Anschutz Medical Campus, Aurora, CO*

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Participant Characteristics

Children and adolescents with special health care needs are often left out of obesity prevention efforts, despite high rates of obesity and related conditions. This paper describes how accelerometers can be used to objectively evaluate physical activity in youth who have special health care needs, illustrated with a case study comparing ActiGraph™ and activPAL™ monitors. The case study profiles a 25-month-old boy with a history of tracheostomy and ventilator dependence resulting in gross motor delays. The child wore two physical activity monitors simultaneously for 24 hours: the ActiGraph™ GT3X+ and the activPAL™. Both monitors have been validated with young children who are ambulatory, but little work has been done using accelerometers on children with special health care needs impacting gross motor movements.

Clinical Implications

Children and adolescents with special health care needs or disabilities are an important and growing population. Pediatric nurses working with children with special health care needs and their families need valid and reliable tools to help them assess physical activity in this population to prevent obesity and related conditions.

Research/Theory Implications

ActiGraph™ and activPAL™ monitors are well-suited for measuring physical activity in pediatrics, including youth with special health care needs. Improving evaluation of physical activity for youth with special health care needs and incorporating high-quality outcome measures, such as accelerometers, are needed.

ActiGraph™ distinguishes activity intensity. ActiGraph™ algorithms are needed for children with special health care needs. ActivPAL™ monitors capture body posture.

With advances in medicine and healthcare, many children born with conditions that were once fatal are living longer lives. Mortality rates continue to improve for prematurity and a variety of birth defects, including congenital heart disease, and spina bifida (Allen, Cristofalo, & Kim, 2011; MacDorman, Hoyert, & Mathews, 2013; Shin et al., 2012; van der Bom et al., 2011). This is exciting progress; however, often these children have special health care needs or chronic conditions. Additionally, developmental disabilities, autism, as well as other behavioral and mental health conditions have been steadily increasing (Boyle et al., 2011; Houtrow, Larson, Olson, Newacheck, & Halfon, 2014). Children with special health care needs may have physical limitations, take medications, and have eating challenges (e.g., food selectivity, swallowing dysfunction, and tube feeding) that contribute to gaining weight more easily than other children (Abeysekara, Turchi, & O'Neil, 2014; Fox, Witten, & Lullo, 2014; Grondhuis & Aman, 2014). As survival rates increase for many medical conditions during childhood, there is an urgent

* Corresponding author: Heather Aldrich, PhD.
E-mail address: heather.aldrich@ucdenver.edu.

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need to address the health disparities in this high-risk population as well as minimize secondary health risks later in life.

Different terminology has been used to describe children with special needs or chronic health challenges – including special health care needs, medical complexity, chronic conditions, functional limitations, and disabilities. Although it is difficult to estimate how many youth are living with special needs due to variations in surveys and overlapping definitions, it is clear that the population is significant and growing (Cohen et al., 2011; Davis & Brosco, 2007). Based on national statistics, children with special needs aged 0–17 are estimated at 12.8–19.3% (Bethell, Read, Blumberg, & Newacheck, 2008). Recent data also show that 19% of children 5–17 years old have limitations impacting mobility, self-care, communication, and/or learning (Child Trends Database, 2014). For the purpose of this paper, we will use the term special health care needs to include any disabilities, chronic conditions, and special needs that have limited development of typical activity.

There is a great deal of evidence that children with special health care needs have higher rates of obesity and related comorbidities than children without special health care needs (Chen, Kim, Houtrow, & Newacheck, 2010; Maiano, 2011; Neter et al., 2011; Rimmer, Yamaki, Davis, Wang, & Vogel, 2011). In a nationally representative survey, 35.3% of children aged 10 to 17 with special health care needs were overweight or obese (defined as having a body mass index [BMI] $\geq$ 85th percentile for age and sex), compared to 30.0% of children without special health care needs (National Survey of Children's Health, 2011/12). Also concerning is that excess weight for many children with special health care needs adds extra challenges to their already compromised health status. For example, excess weight increases a child's risk of asthma, mobility difficulties, low self-esteem, metabolic syndrome, and other secondary conditions (Barlow, 2007; Daniels, 2006). Adding these risk factors on top of the health challenges already faced by a child with special health care needs can complicate or exacerbate the child's present condition and quality of life, and, in the long-term, impact their health in adulthood (Kim, Conners, Hart, Kang, & Kang, 2013; Reinehr, Dobe, Winkel, Schaefer, & Hoffmann, 2010; Yamaki, Rimmer, Lowry, & Vogel, 2011). American adults who have disabilities and are obese have higher rates of diabetes, hypercholesterolemia, hypertension, and higher levels of circulating C-reactive protein than obese adults without disabilities (Froehlich-Grobe, Lee, & Washburn, 2013).

Most obesity prevention interventions exclude children with special health care needs (Froehlich-Grobe & Lollar, 2011; McPherson, Keith, & Swift, 2014; Minihan, Fitch, & Must, 2007). Recent review articles looking at obesity prevention for children with special health care needs show a significant gap in evidence-based obesity prevention efforts (Maiano, Normand, Aime, & Begarie, 2014; McPherson et al., 2014). Of the research studies found, there was a lack of rigorously designed studies, long-term follow-up, and adequate sample sizes (Maiano et al., 2014; McPherson et al., 2014).

The importance of establishing healthy physical activity habits in childhood is well documented (Jones, Hinkley, Okely, & Salmon, 2013; Schwartz, Scholtens, Lalanne, Weenen, & Nicklaus, 2011), but often not addressed with children who have special health care needs (Froehlich-Grobe & Lollar, 2011; Minihan et al., 2007). Additionally, many children with special health care needs have unique challenges that may not be addressed by the usual activity recommendations for their age group. Research has shown that children with special health care needs participate less in physical activity and community activities than other children (Bedell et al., 2013).

One of the challenges to including children with special health care needs in health promotion efforts is that more research needs to be conducted using rigorous outcome measures, such as using accelerometers to measure physical activity and inactivity. Although there have been a few studies conducted using accelerometers in children with special health care needs, mainly cerebral palsy (Gorter, Noorduyn, Obeid, & Timmons, 2012; McAloon, Hutchins, Twiste, Jones, & Forchtner, 2014; Oftedal, Bell, Davies, Ware, & Boyd, 2014) and intellectual disabilities (McGarty, Penpraze, & Melville, 2014), there is a critical need for more well-designed studies using accelerometers with diverse populations of children with special health care needs. The purpose of this paper is to describe how accelerometers can be used to evaluate physical activity for children with special health care needs and to illustrate with a case study comparing two monitors.

Methods

The case study profiles a 25-month-old boy with a history of tracheostomy and ventilator dependence resulting in gross motor delays. At the time of this case study, the toddler was able to stand with some support but was not cruising or walking. He also was able to scoot on his bottom while sitting up, with minimal formal crawling. The child wore two physical activity monitors simultaneously for 24 hours: the ActiGraph™ GT3X+ (ActiGraph, LLC: Pensacola, FL) and the activPAL™ (PALTechnologies: Glasgow, Scotland). Both monitors have been validated with young children who are ambulatory (Cauwenberghe, Gubbels, De Bourdeaudhuij, & Cardon, 2011; Davies, Reilly, McGowan, et al., 2012; Pate, O'Neill, & Mitchell, 2010), but, to our knowledge, little work has been done using accelerometers on children with special health care needs impacting gross motor movements. The parent was instructed to have the child participate in usual activity for the day. The parent kept a detailed journal of the child's activities, including a description of the activity, and time (to the nearest minute) when the activity (including meals and sleep time) began and ended. The case study was determined non-human