

Moving towards a better understanding of well-being for children with complex disabilities from using the Innowalk

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Introduction

Children with more severe physical disabilities are limited in their ability to participate in physical activities and exercise. It is known that increasing physical activity levels improves well-being across the general population, including children without disabilities. Whether this is so for those children who have mobility limitations and cannot communicate their feelings, is currently unknown. Well-being has different definitions and is especially problematic to measure, for those whose ability to speak is reduced¹. This research is observing non-ambulant children using the Innowalk^{2,3}(Figure 1), a robotic device, as one context for them to indicate their well-being, to support the development of a new well-being scale (WEBS).

Patient and methods

Ten children aged four to eighteen, with a range of physical and learning disabilities, supported by their parents in a special school context. A consultation group includes two young adults with cerebral palsy. Exploratory case study series made up of observations (field notes), scoring PRIME-O⁴ and Be well checklist⁵ and the new well-being scale, plus parental reported diaries and child/ parent interviews. Preliminary constructs being tested in the new proposed well-being scale, based on PhD data and the research advisory group (shown in Figure 2) include calmness, comfort, creativity, energy levels, engagement with other people or activities, expressing joy⁶.



Figure 1: © Innwalk, Made for Movement

Proposed new well-being scale: Figure 2

Well-being scale (WEBS)						Well-being scale (WEBS)					
Name	Age	Level of GMFCS I II III IV V	Observation Session number	Timing length of session (minutes)	Date	Comments: how the energy to participate					
Calmness						Descriptor	Poor	Low	Usual	Good	Excellent
Comments- e.g. calmness in mood- excitability or withdrawn						1	2	3	4	5	
Comfort						Descriptor	Poor	Low	Usual	Good	Excellent
Comments- e.g. settled in equipment, internal spasms, flex observed, self-reported behaviours reduced to g-reflux, hand in mouth to reduce pain, eye pressing, head banging						1	2	3	4	5	
Creativity						Descriptor	Poor	Low	Usual	Good	Excellent
Comments- expressing self in different ways e.g. music/ drawing/ calligraphy						1	2	3	4	5	
Energy levels						Descriptor	Poor	Low	Usual	Good	Excellent
Comments- e.g. could be smiling or laughing, expressive sounds indicating pleasure						1	2	3	4	5	

Person completing the observational well-being scale
Role or Relationship to Child/ Young person _____
Supported by _____
Activity participated in _____

Figure 3: Qualitative comments so far



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Results

Data is still being analysed using Braun and Clark's six stages of analysis⁷. Figure 3 highlights some quotes. In addition to academic papers, funding is being sought for an accessible booklet to be produced for the participants: 'My well-being stories about the Innowalk'.

Conclusion

The observational well-being scale being developed will potentially enable the content validity to be evaluated in a future larger study, to test out the psychometric properties of this proposed well-being scale (WEBS) in wider contexts.

References:

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