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ORIGINAL RESEARCH: EMPIRICAL RESEARCH–QUALITATIVE

Conceptualization of physical exercise and keeping fit by child wheelchair users and their parents

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Abstract

Aim. To gain a better understanding of how children aged 6–18 years who use wheelchairs and their families conceptualized physical exercise and keeping fit.

Background. Disabled children with reduced mobility are commonly overweight and unfit. Nurse-led health screening programmes in schools commonly exclude disabled children if they cannot use standard weighing scales or stand against height measuring sticks.

Design. Qualitative interview study at two time points over 6 months with children who use wheelchairs and their families.

Methods. Framework analysis using the theory of planned behaviour.

Findings. Mainly physically active participants were recruited (24 children and 23 parents) 2013–2014. Despite engaging in high levels of physical exercise, children were assessed as fit but had elevated body fat and did not realize how fit they were or that they were slightly overweight and nor did their parents. Children enjoyed the social benefits of exercise. Unlike their parents, children confused the purpose and outcomes of physical exercise with therapy (e.g. physiotherapy) and incorrectly understood the effects of physical exercise on body function and strength, preventing stiffness, increasing stamina and reducing fatigue. A new model was developed to show children's misconceptions.

Conclusions. Proactive parents can overcome barriers to enable their children to benefit from physical exercise. Professionals need to increase communication clarity to improve children's understanding of therapy compared with physical exercise outcomes. Inclusion of children who use wheelchairs in health education policy; routine health screening; physical education classes and teacher training requires improvement. Body composition measurement is recommended, for which nurses will need training.

Keywords: conceptualization, disabled children, health promotion, nursing, physical exercise therapy, public health, qualitative, school health screening, wheelchair

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Why is the research needed?

- Children's health policy on exercise and healthy eating and national school weight screening programmes frequently exclude disabled children and they are often not screened if they cannot use standard weighing scales and height sticks.
- Disabled children and particularly those with reduced mobility who use wheelchairs are at high risk of being unfit, overweight or obese.
- It is not known how children who use wheelchairs and their parents conceptualize physical exercise, keeping fit or obesity.

What are the key findings?

- Children who use wheelchairs were assessed as fit but had elevated body fat and did not realize how fit they were or that they were slightly overweight and nor did their parents.
- Children who use wheelchairs confused the different purposes and outcomes of therapy (such as physiotherapy) compared with physical exercise, whereas parents were clear about the differences.
- The study attracted self-selecting wheelchair using child participants who generally engaged in high levels of physical exercise, which is useful feasibility information for the future design of interventions and research.

How should the findings be used to influence policy/practice/research/education?

- Findings show that child participants who used wheelchairs were commonly excluded from nurse-led school screening programmes as the measuring equipment was commonly not accessible and an alternative accessible method was not available. This requires addressing urgently to comply with Equality Legislation.
- Professionals in the multi-disciplinary team and especially nurses, need to clarify the language shared with children who use wheelchairs to ensure that they are clear about the difference between the purpose and outcomes of therapy (such as physiotherapy) compared with physical exercise.
- Future intervention development and research design should take account of unfit children who use wheelchairs and their parents being unlikely to volunteer to participate in research studies exploring children's fitness.

Introduction

There is concern about increasing obesity among children in high-income countries (Department of Health 2011, WHO 2015). Children who use wheelchairs are at higher risk of being unfit, overweight or obese (Public Health England 2014). In England, 45% of children age 8–13 years with a life-limiting illness and learning disability were obese or overweight in 2011 compared with 22% of children who had neither condition (ChiMat 2011). Being overweight has a severe impact on health and well-being in childhood and adulthood by exacerbating underlying conditions and increasing the risk of type 2 diabetes, heart and liver disease and some cancers (PHE 2014).

Despite the greater prevalence of obesity and overweight in disabled children, policy has primarily focussed on typically developing children. Neither the United Kingdom, guidance on exercise for children (National Institute for Health and Clinical Excellence (NICE) 2009) or the American Academy of Pediatrics Committee Statement on Nutrition (AAP 2003) mentioned disabled children. A balanced healthy diet tailored to each disabled child and regular physical exercise to keep-fit has been shown to be safe with the same benefits as for typically developing children (O'Brien *et al*. 2014, 2016).

An effective keep-fit physical exercise involves the child feeling hot and sweaty with an increased heart and respiratory rate (thereby indicating an increased metabolic rate) that subsequently returns to normal. Keep-fit exercise also induces a pleasant feeling of well-being. In contrast, therapies such as physiotherapy are designed to maintain, regain or improve strength, mobility or function of a specific element of the musculoskeletal system and children rarely experience pleasant feelings or social benefits (Scianni *et al*. 2009). Having regular therapy facilitated by a therapist does not replace the need for frequent physical exercise as they serve different purposes.

Background

The linked study protocols outline in greater depth that nurses have a vital health promotion, motivational and monitoring role in optimizing the health and well-being of disabled children (O'Brien *et al*. 2014, 2015). In England, children are weighed and measured by nurses as part of the National Child Measurement Programme at age 4–5 years and 6–10 years. Guidance recommends exclusion of children who are 'not able to stand unaided on the scales or under the height measure' (DoH 2010, p. 9). The trigger for intervention (such as a letter to the parents or exercise referral) is the outcome of the child's weight and height measurements. Parents and children also need to recognize that the child is overweight and unfit and to acknowledge that this situation is unhealthy.

Little research has been conducted to understand why disabled children have lower participation in physical

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exercise and are generally less fit (Scott 2010). Although there is increasing understanding of how typically developing children and their parents conceptualize fitness and obesity (Thomas *et al.* 2014), there is no clear understanding of how children who use wheelchairs conceptualize these issues. The purpose of this paper is to report the first findings on how children who use wheelchairs and their parents conceptualize exercise and keeping fit.

Theoretical framework

The Theory of Planned Behaviour (Ajzen 1991) was used to conceptually link attitudes towards behaviours, subjective norms and perceived behavioural control as shaping an individual's behavioural intentions and actual behaviours. (See Data S1 in Online file 1).

The study

Aim

To gain a better understanding of how children aged 6–18 years who use wheelchairs and their families, conceptualize physical exercise and keeping fit and the impact of physical exercise on children's bodies.

Research question

How do children (and their parents), conceptualize physical exercise and keeping fit and the impact of physical exercise on children's bodies?

Design

The SPICE framework (Setting, Perspective, Phenomenon of Interest, Comparison, Evaluation; Booth 2006) was used to determine the study focus (Table 1). This generic qualitative study informed by Framework analysis (Spencer *et al.* 2003, Carroll *et al.* 2011) was a component of a larger mixed-method study exploring and measuring well-being, health and fitness in children who use wheelchairs (O'Brien *et al.* 2014).

Participants

Twenty-four children and 23 family members took part in one-to-one interviews at time point 1 in study stage 1 and 16 of these children and 15 parents took part in subsequent family-based discussions at time point 2 around 6 months later in study stage 3 (Figure 1).

(See Tables 2 and 3) for sample characteristics for each time point. Letters of invitation were sent via wheelchair services, not-for-profit organizations and snowball sampling. A purposive sampling frame (Table 4) was designed to capture maximum variation of conditions and equal number of children per age group (6–10, 11–15, 16–18 years).

Data collection

Data were collected on two occasions between October 2013 - September 2014. Structured interviews were conducted face-to-face or by telephone with children and their parents to elicit experiences and opinions and to explore their understanding of 'keeping fit'. Parent and child interviews were conducted separately, apart from when parental assistance was required to enable participation. Interviews were audio recorded and transcribed verbatim. Around 6 months later, 'structured discussions' were conducted at a 'family day' at a child-centred meeting venue in a country park. We termed these structured 'discussions' and not 'interviews' as the purpose was to elicit feedback and check out our understanding of findings from previous episodes of data collection and to further explore specific issues of interest for further clarification. Key information from discussions was recorded on pro-forma sheets in real time.

Ethical considerations

See the study protocol for full details about child safeguarding, consent procedures and data protection (O'Brien *et al.* 2014). In brief, written informed consent and proxy consent for children (6–15 years) to participate was obtained from parents; and assent to participate was established with children and recorded on an assent form. Children over 16 years with mental capacity provided written informed consent. Research Ethics committee approval was obtained on 23 August 2013.

Data analysis

Interviews were conducted in English or Welsh and analysed in the original language. Welsh transcripts were then translated into English for further in-depth analysis. Interview transcripts and completed proformas were uploaded into Atlas.ti software version 6 (Atlasti 2011). The Framework analytical approach (Spencer *et al.* 2003, Carroll *et al.* 2011) was used by two researchers to map participant's perspectives against the Theory of Planned Behaviour (Ajzen 1991)-(see Figure 2). Parent and child data were identified with separate codes that could be linked. Two other researchers rechecked the initial descriptive coding, further interrogated, analysed and interpreted the evidence

Table 1 Spice Framework.

Setting	Perspective	Phenomenon of interest	Comparison	Evaluation	Methodological approach
Children 6-18 yrs who use wheelchairs in the UK	Children, young people and parents	Conceptualization of being fit, keeping kit and what keeps you fit and how keep-fit activities affect the body (outcomes of keep-fit)	Children and young people's views compared with parents, compared with policy and literature	Thematic analysis of interview transcripts using the 'Best Fit' Framework approach and the theory of planned behaviour	Qualitative data derived from structured interviews and 'discussions' individually and in family groups

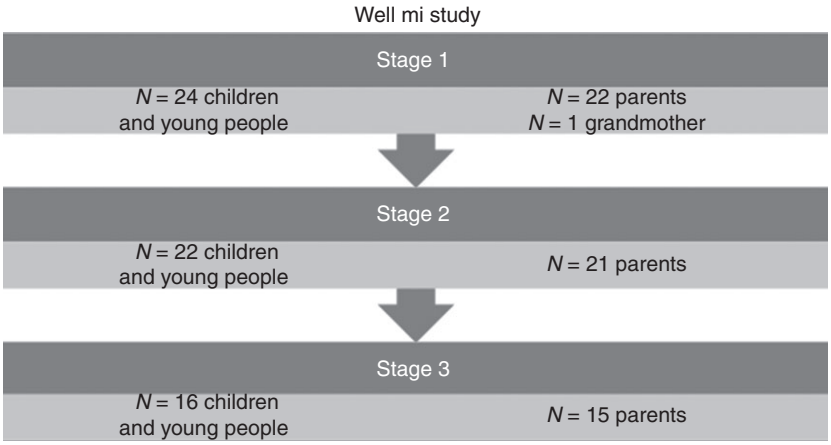

Figure 1 Flow chart showing the participant flow (and sequential drop out) in the well mi study. This study accessed participants in stages 1 and 3.

and developed maps and charts to display analytical findings.

Validity and rigour

None of the researchers had any prior relationship with the children and their families and disengaged at the end of the study. Rigour was enhanced by prolonged engagement with participants with opportunities to check meaning of initial analyses. The multi-disciplinary team included nursing, physiology, psychology and sports science expertise, which enabled interpretation through different discipline-specific lenses. An advisory group including a young adult wheelchair user, exercise/sports facilitators, therapists and wheelchair services representatives supported and advised the research team and provided feedback on findings.

Findings

Mapping findings against the theory of planned behaviour

Descriptive level findings are mapped against the theory of planned behaviour in Table 5.

Behavioural intention and actual behaviour

Twenty-one of 24 children reported that they regularly participated in a wide range of sports and physical exercise. The mean number of organized physical exercise sessions per week was three, with four children reporting at least four physical exercise sessions a week. Only three children reported none or less than one physical exercise session a month. Of the three children that did not regularly participate in physical exercise, their parents were all keen for them to engage in more keep-fit activities. Overall, the very high physical exercise and fitness levels that we measured were not typical of the general population of wheelchair using children. We will return to this issue in the discussion.

Attitudes

Enjoyment and loving the activity was a key motivator. A girl aged 9 years (W22) said: 'Now, we've got a topic in PE (physical education class at school), which is tennis–and I …absolutely love doing that'. A girl, aged 12 (W13)

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Table 2 Child demographic characteristics (n = 24) at time point 1.

Gender	12 (50%) Male
	12 (50%) Female
Aged 6–10	8
Aged 11–15	8
Aged 16–18	8
Condition	
Achondroplasia/Pseudoachondroplasia	2
Cerebral palsy	14
Down's syndrome	2
Encephalitis	1
Osteoporosis	1
Pallister–Killian syndrome	1
Spina bifida	2
Other unknown cause of mobility impairment	1
Education	
In special education	11
Not in special education	13
Ethnicity	
White British	20
Other white background	1
Mixed race	1
Black African background	1
Mixed Asian background	1

Table 3 Child demographic characteristics (n = 16) at time point 2 (phase 3).

Gender	8 (50%) Male
	8 (50%) Female
Aged 6–10	5
Aged 11–15	6
Aged 16–18	5
Condition	
Cerebral palsy	10
Down's syndrome	1
Encephalitis	1
Osteoporosis	1
Pallister–Killian syndrome	1
Spina bifida	2
Education	
In special education	9 (56%)
Not in special education	7 (44%)
Ethnicity	
White British	13
Mixed race	1
Black African background	1
Mixed Asian background	1

described her experiences of using the Wii fit: Girl: 'Because like, one it's really fun and like, two it makes me feel better to know that I'm doing something'.

Older children were particularly motivated by the individualization of some schemes and the social aspects of participation. For example, A young man aged 18 (W17) said: 'There are quite a few people my age and then there are various adults of various ages as well…. it's mostly men…there are only two or three women or girls that go…'. Researcher 'But it's the social thing that keeps you going?'. Young man: 'That's the primary motivator'.

Similarly, a young woman aged 18 talked about the benefits of exercising with friends: 'Making friends with people and keeping fit with each other because sometimes, it's nice to have a friend, if you're doing exercises with them, to look at them and see what they achieved and you kind of like achieve something together'. And a boy aged 14 (W06) said:'…because we all like train once a week and you get to build up some really good strong bonds, so it's really good'.

Parents all said that physical exercise to keep-fit was very important along with enjoyment. For example, a mother of a girl, aged 9 (W24) said that she would like her daughter to take part in exercise for the joy of doing it: 'I want her to do it for the love of doing it….. Not for competition or matches…'. Likewise parents of severely disabled children were motivated to enable their children to experience physical exercise: A mother of a girl aged 8 (W24) said: '(daughter) is very limited in what she can do, but she goes to a private swimming lesson every week'.

Expected outcomes

In addition to social contacts and friendships, children of all ages generally expected increased function and strength, prevention of stiffness and increased stamina and reduced fatigue from physical exercise.

Experienced outcomes of keep-fit activities

Children age 6–10 experienced increased tiredness and confidence. A 9-year-old girl (W22) said: 'I get worn out' (doing exercise). Later she went on to explain that exercise had also given her the confidence to do other things.

Children age 11–15 commonly experienced increased effort and hard work associated with exercise and felt better and healthier afterwards. Although a boy aged 14 (W10) did not define what he meant by 'keeping healthy' he said: 'I would just do it [physical exercise] to keep healthy, because the alternative to that is just sitting at home, doing nothing'.

The older 16–18 group experienced increasing confidence, stamina and reducing aches, fatigue and stiffness and some said they maintained their independence. Some young people who did not have degenerative conditions also increased their mobility. For example, A young woman

Table 4 Child participant inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
● Children aged between 6 and 18 years with a mobility impairment and issued with a wheelchair, were eligible to participate along with family members.	● Children who were not wheelchair users; had significant challenging behaviours who may have posed a potential risk to themselves, others or the researcher during aspects of data collection such as physiological monitoring and testing of equipment; or had significant mental health issues, or their disability may hinder participation (such as not being able to communicate).

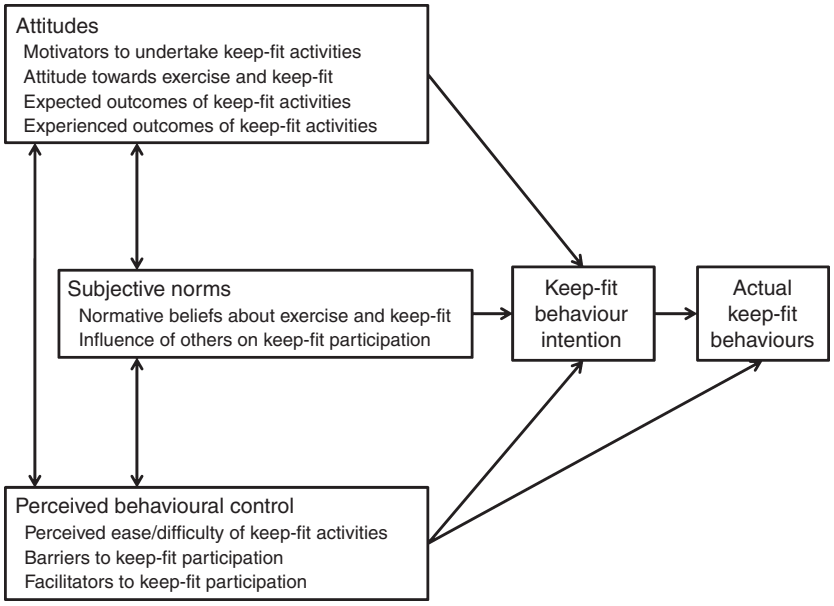

Figure 2 Theory of planned behaviour framework (Ajzen 1991).

aged 18 years (W23) said she swam because: 'The reason is… to keep myself mobile and stop me, because of my cerebral palsy, to stop my legs getting stiff because if they were stiff I wouldn't be able to do anything and I would class myself as an independent person because I do like loads of arm stretches, to help with my personal care and things'. This quote also illustrates how therapy-type activities were prioritised to achieve daily functioning outcomes such as reduced stiffness.

Similarly, a young man aged 18 years (W17) said that he did physical exercise to avoid fatigue: 'Well, it's important for me to keep-fit because of my.. general life. Because, I have quite bad fatigue issues, I have to kind of keep my stamina up. Or else I get very, very tired, very, very quickly. So keeping fit does a lot in terms of making my life easier to live… I notice if I stop maintaining my fitness for a few weeks, pushing (self-propelling the wheelchair) becomes more difficult and I become more tired and things like that, so…. to start with, the reducing fatigue and the increase in stamina were kind of happy side effects because I was going and I still go to basketball for the social aspect of it. It's just now become the–because I've noticed the increase in stamina and that kind of thing that is an additional motivator, but I don't think that it would ever be the primary motivator'. This young man recognized how the improved fitness resulting from physical exercise improved his energy and stamina and experienced those benefits as combatting his condition, which is logical because it is the present that has an impact on his daily life and not the risk of later secondary diseases, such as cardiovascular disease or diabetes.

Perceived behaviour control

Children were commonly placed in inappropriate classes or received an inappropriate level of assistance at school physical education (PE) lessons. Participation in school-time PE lessons varied significantly between children, especially those in main-stream schools who participated less than children in Special schools. Many children were

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Table 5 Descriptive level findings mapped against the theory of planned behaviour.

Actor	Attitudes Motivations, attitudes Expected outcomes Experienced outcomes			Perceived behavioural control Ease/difficulty Barriers/facilitators	Subjective norms Normative beliefs Influences of others	Keep-fit behaviour intention	Actual keep-fit behaviours	Physical activity levels
6–10 years	Motivations attitudes: Fun Loved doing exercise Challenging Important	Experienced outcomes: Feeling blood pumping Feeling hot and sweaty Feeling tired Feeling confident Feeling better	Expected outcomes: increased function and strength, prevents stiffness; Increased stamina and reduced fatigue, social friendships	Activities could be hard and tiring (not usually easy) Barriers: Transport to activities Joining activities for first time Access to facility Exclusion from activity Local availability of activity Exclusive use of facility minimizes frequency of activity Availability of parents Need a specific wheelchair Juggling with therapy appointments Inappropriate class Inappropriate level of assistance Worsening condition prevents participation in physical activity Facilitators: were generally when barriers had been removed or did not exist	Physical activity maintains function and strength Increases stamina and reduce fatigue Physical activity outcomes generally confused with therapy outcomes to maintain function and strength. None of the young people weighed or measured at school or GP Ongoing influence of physical therapists Positive influence of staff and individualized exercise referral scheme Wheelchair-specific keep-fit information important	3 did not take part in any or less than one activity a month and had little intention to do so – but they were receiving therapy with a therapist 21 children and young people were positive about engaging in keep-fit activities and wanted to try more and varied activities Wanting to prevent deterioration	Floor work, PE lessons, Horse riding Swimming, archery, cycling, hula hoops, tennis, trampoline, yoga	Mean number of organized physical activity sessions × 3 per week 4 children > × 4 sessions per week. X3 none or less than one activity a month
11–15 years	Motivations attitudes: Enjoyable Social benefits Friend motivation	Experienced outcomes: Feels like hard work Feeling better Feeling healthier					Canoeing, circuit training, disabled skiing, gym, PE lessons, horse riding, school sports day, standing frame, walking aid, swimming, treadmill, wheelchair basketball, wheelchair zumba in usual class, wii games	
16–18 years	Motivation attitudes: Important Enjoyable Promotes independence/ mobility Social benefits Group motivation	Experienced outcomes: Feeling good Feeling healthy Feeling fit Maintaining independence Maintaining mobility					Football, walking aid, physiotherapy standing frames, walking frames wheelchair basket ball, wii games,	
Parents	Very important for health Very important to keep a healthy weight Promotes sleep Want children to take part in exercise Physical exercise is different from physiotherapy			Barriers: Insufficient time Having to transport children to activities Insufficient childcare for other children Lack of motivation Cost	Physical activity should be enjoyable and competitive Therapy (maintaining strength and function) competing priority with physical activity Parents more influenced by their own beliefs with less influence of clinicians and therapists	Many parents wanted to keep themselves fit Some thought children did enough PE at school A few thought that children were not doing enough keep-fit activity	Many parents also exercised to keep-fit.	

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discriminated against by being excluded from PE lessons at mainstream school. Children reported many different examples of alternative activities, such as: Researcher: 'What do you do when the children in your class go to PE lessons?'... 'Well, I have to judge their skills'. Girl aged 12 (W13). In contrast, Special schools appeared to provide more opportunities: For example, the mother of a boy aged 9 (W16) explained about the bike club that her son attended: 'It's a school based one and he's just got a specially adapted trike from a charity for himself'.

Some older children intended to maintain a stable physical condition but created perceived barriers. For example, a boy aged 14 (W10) had an attitude that it was going to be difficult to sustain a sufficient level of physical exercise to prevent his condition deteriorating: 'but trouble is I don't think I get enough exercise, I want to do more exercise, but then when it comes to it I'm thinking, well, I'm thinking it's going to be a lot of work, but, I do want to keep-fit, because obviously if I don't keep-fit,... my condition is going to get a lot worse'. He was unclear as to what could help him to overcome this attitude and he was not probed about what could help him overcome his own behavioural control (such as making the exercise fun rather than a lot of work). Nonetheless, he shows that he contextualises keeping fit as important for his medical condition.

Along with cost, accessibility, locality and lack of childcare, barriers to participation commonly included lack of parental time. A mother of a girl aged 8 (W30) explained: 'I honestly cannot see that I'll get a chance [to take her to an activity].... And and to be honest I haven't got the energy..... Because I work and then I've got (name of girl) so.... it's really difficult with a disabled child'.

Grandparents frequently stepped in to provide additional support: 'Grandparents, they help me a lot' (Boy aged 14 W10), whose grandparents took him swimming on a weekly basis and looked after him when his parents were at work. Despite the time constraints expressed by many parents, some were very resourceful and facilitative at home. For example, a mother of 8-year-old girl (W24) said: 'We do a bit of yoga every morning'.

Due to limited time and having to attend several health-related appointments, some parents were forced to prioritise attendance at therapy sessions (maintaining function) over keeping fit activities (staying healthy). For example, one father said that his son (aged 14) now attended two sessions of private physiotherapy per week on a Saturday. Father (W10): 'He used to go to (name of a club) which was for disabled kids and he'd go–and I think he did horse riding on that and he did the trampoline and basketball and stuff like that–he did everything. But that is on a Saturday morning, which is when he has physio now, so we had to stop just for a few years'. Similarly, some children had physiotherapy instead of attending PE lessons at school.

Children also frequently needed additional sport-specific wheelchairs that were not available through the local wheelchair service and parents were not always aware when they were available in local sports groups/providers. The father of a girl aged 11 (W02), for example, said that his daughter had shown an interest in wheelchair racing, but she did not have a suitable wheelchair and he was not aware that many clubs provided wheelchairs: 'I took part in the (Name of city) Great Run, a couple of years ago and she's seen the wheelchairs going–they go off first and she wanted to follow-them–she tried to go through the barrier to follow them around. And it's like, well I would take her down there (to the local athletics track), but if I take her down there I need to sort out a wheelchair, because that chair isn't suitable to go around the track'...'But even saying that, I priced up a proper racing wheelchair, like they have in the Paralympics and I priced up one of them...which isn't too, too bad a price. Just getting the money to pay for it'.....'The NHS would only supply one chair'.

Subjective norms and conceptualizations of physical exercise and keep-fit compared with therapy

None of the children or their parents could remember the last time that the children were weighed or had their height measured in any context. Until we told them the results of their child's physiology tests, they had no clear idea as to their child's height, weight, body mass index or fitness status, other than how their children looked or felt when handled. In contrast, they recognized that the physiotherapist, who many regularly attended, measured their therapy outcomes to assess progress and re-set therapy goals.

Child and young people's perspectives

Irrespective of age, children commonly identified that taking part in physical exercise would improve function and strength, which would help to increase their stamina and reduce their fatigue, with little mention of fatness or healthy weight and metabolic, heart or respiratory health. Of particular note and significant importance, apart from the social aspects, the main children's motivator to take part in physical exercise was to maintain function, which is a key aim of therapy and not keeping fit (Table 4). The language used by children and young people when talking about physical exercise was commonly the language associated with 'therapy' (function, strength, mobility, stiffness, contracture, fatigue, stamina). Children and young people

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also commonly stated that they wanted to maintain functional mobility to achieve future goals through exercising.

Children commonly talked about their physiotherapy exercises as physical exercises and other sports related activities in the same sentence. For example, a 9-year-old girl (W22) said: 'Because I like staying healthy and with the clubs it helps me exercise and also I do physio(therapy) at school sometimes'.

Further illustrations of this narrow conceptualization of outcomes of physical exercise and their overlap and dependence on therapy outcomes include a boy aged 11 (W11) who said that exercise was very important to him to improve strength and function: '....because exercise is really, really important to me, because, I need, I need it to strengthen my bones and just to get better at walking and actually moving about'. A young woman aged 18 (W23) said that participating in exercise stopped her from becoming stiff: 'Keep-fit means, sort of like, when you've got someone in a wheelchair, if you don't do, like, keep-fit, you end up getting stiff, so, it's important to me'.

Unless prompted, children did not usually make the immediate association between physical exercise and health benefits such as a healthy heart, lungs and healthy weight. Following direct prompting a girl, aged 6 (W09) answered as follows: Researcher: 'What do you do to keep healthy?' Girl: 'I eat apples, grapes, oranges, not bananas but raisins'. Researcher 'Do you do exercise to keep healthy as well? Do you move your body around?'. Girl: 'Yes, for my cerebral palsy, I do'. In doing so, the researcher re-orientated her to think about the association between moving her body around and keeping healthy, but her answer was still orientated to her medical treatment and therapy.

When asked to talk with further prompting about the specific effect of named physical exercises that they participated in on their bodies, children could mostly make the association between physical exercise and the physiological response. Most children made the link to feeling good (a key motivator for exercising) and the sensations associated with exercise such as feeling hot and sweaty and experiencing an increased heart rate. With prompting, most children recognized that these sensations contributed to them feeling good after exercise. For example, a girl aged 9 (W22) said that exercise was good to get the heart pumping: 'It just makes it pump more blood out and you need blood in your body because that's really important'.

There was some evidence of disconfirming cases when children responded unprompted by the researcher. A few children seemed to begin to superficially differentiate between therapy and physical exercise but without explaining the different expected outcomes.

Individual influences

Specific individual influences included a young man aged 18 (W17) who said that exercise referral staff were influential: 'I thought I would join the gym so I thought I could have a more kind of personalized programme, obviously because the people that normally work in the gym, aren't used to working with people with my kind of impairments, whereas the people who run the exercise referral scheme are'.

Parent perspectives

In contrast, most parents could distinguish the differences between keep-fit and therapy. The grandmother of a 6 year old girl (W09) explained: 'when she does these [therapy] exercises at home... it's not for keeping generally fit–it's for specific things–specific ways of moving and keeping balance in the core and strengthening in her core and all this. She doesn't really like having to do these things [therapy] every day, but they are very necessary and you've got to do something when you are older, I mean I would like her to do something which involves a bit of competitiveness which is enjoyable and specific to keeping fit, rather than keeping able, you know, but they are two different things but they are linked aren't they?'.

There were some disconfirming cases such as a parent with an 8 year old child (W30) who had severely limited mobility who appeared to conceptualize physiotherapy as keep-fit exercise when asked about keeping fit: '...she's regularly in a standing frame. She goes to hydrotherapy every other term, once a week'. Likewise, the father of W11 (11-year-old boy) said that his son took part in physical exercise to re-build all the strength and balance after a major operation:'....he had the (named) surgery and then, it's basically well he was ten, a ten year olds body on a new born baby's legs because all his spasticity had gone so we're just trying to re-build all the strength and balance and what not'.

Parental influences

The information on physical exercise, keeping fit and therapies given to families by a range of professionals including disability sports officers, school staff, social workers and physiotherapists had a positive influence and impact on the normative beliefs of some parents. Information received ranged from specific therapeutic exercises to reduce stiffness and pain, to more general advice such as promoting keep-fit exercise and reducing sedentary lifestyle and maintaining a healthy weight. The family of an 11-year-old girl (W02) received the following advice 'Keep her active to maintain her weight. Maintain her weight throughout her life as it is easier to manage'.

Wheelchair services were not noted as a means of accessing advice about keeping fit.

Theory development

By mapping the subjective norms and conceptualizations of children and young people compared with parents we could create an analytical model showing some distinct differences and misconceptions (Figure 3).

Discussion

We report the first evidence as to how children who use wheelchairs and their parents conceptualized physical exercise, keeping fit and the impact of keep-fit activities on children's bodies. The children conceptualized their health and fitness differently to typically developing children who are more acutely aware of their weight (Thomas *et al.* 2014). Unlike their parents, children across the age range broadly confused the purpose and outcomes of physical exercise with therapy and incorrectly understood the effects of physical exercise on body function and strength, preventing stiffness, increasing stamina and reducing fatigue. The language associated with therapy is likely to have been engrained from a young age when they were first exposed to therapists and therapy interventions. We believe that more appropriate and more consistent language and terminology needs to be used during interactions with these children and their families so that keep-fit activities and benefits are better described, differentiated and understood.

Although confused about the anticipated outcomes of physical exercise, children experienced wide-ranging positive impacts and social and health benefits from regularly participating in physical exercise. A recent systematic review likewise showed that children conceptualized their wheelchair should provide more than just mobility and should include a range of lifestyle benefits and opportunities for participation in physical and social activities (Bray *et al.* 2014). Even some outcomes perceived as a negative impact, such as being tired after exercise in the short term, could be considered positive, as it indicates an exercise intensity that was likely physiologically beneficial.

Nonetheless, these important new findings need to be contextualised in the specific context of an atypical group of 24 wheelchair using children, 21 of which actively engaged in physical exercise and bucked the international trend for being very overweight with highly elevated body fat. The results of physiological assessments showed that the children had good levels of cardiovascular fitness and healthy metabolic profiles. Despite high levels of physical exercise, their body fat levels were still higher than desirable. Improved levels of cardiovascular fitness and metabolic profiles were also reported in our systematic review of physical exercise interventions (O'Brien *et al.* 2016).

We think it possible that the subjective norms of these highly active and atypical disabled children are likely to have a multi-directional interaction that contextualised their (mis)understanding and conceptualization of keeping fit and physical exercise. Their misconceptions about expected outcomes of physical exercise (which were more aligned with therapy outcomes) inadvertently contributed to motivating them to do more physical exercise and conversely physical exercise participation influenced their subsequent conceptualizations of the benefits of keeping fit.

Although there were exceptions, parents of the atypically fit children were generally also engaged in physical exercise and understood the benefits of keeping fit. Parents did not appear to conceptualize their children as particularly 'fragile' or any less in need of maintaining general health and fitness compared with typically developing counterparts. They did not seem to be overly 'protective' (a common coping style of parents of disabled children, see Antle *et al.* 2008, Guite *et al.* 2011) and despite the extra effort required and recognition of the numerous barriers, they managed to transport their children to physical exercise activities. Some parents also supported simple keep-fit exercises at home on a regular basis. Exercise had become a pleasant habit and a routine in children's lives and they liked the feeling of well-being in the same way as typically developing children.

Despite the importance of weighing and measuring children in universal child health screening programmes none of the 24 children or their parents could remember when they were last weighed or knew what they weighed until we told them (Department of Health 2010). Children attended both mainstream and special schools and although it may be assumed that special schools would be more likely to have accessible weighing scales and height sticks, the children who attended special schools and their parents could not recall their children being weighed and measured. Children who attended special schools did, however, generally have greater access to physical exercise and sporting activities.

All parents were pleased to hear about their child's level of fitness but surprised about their weight and fat levels. Although some children could potentially stand against standard height sticks, lower limb muscle weight often makes it impossible to grade these children into the usual BMI categories (based on weight and height). Our wider study to develop simple methods to measure health and fitness in mobility-impaired children in non-clinical settings has established 'proof of concept' that it can and should be

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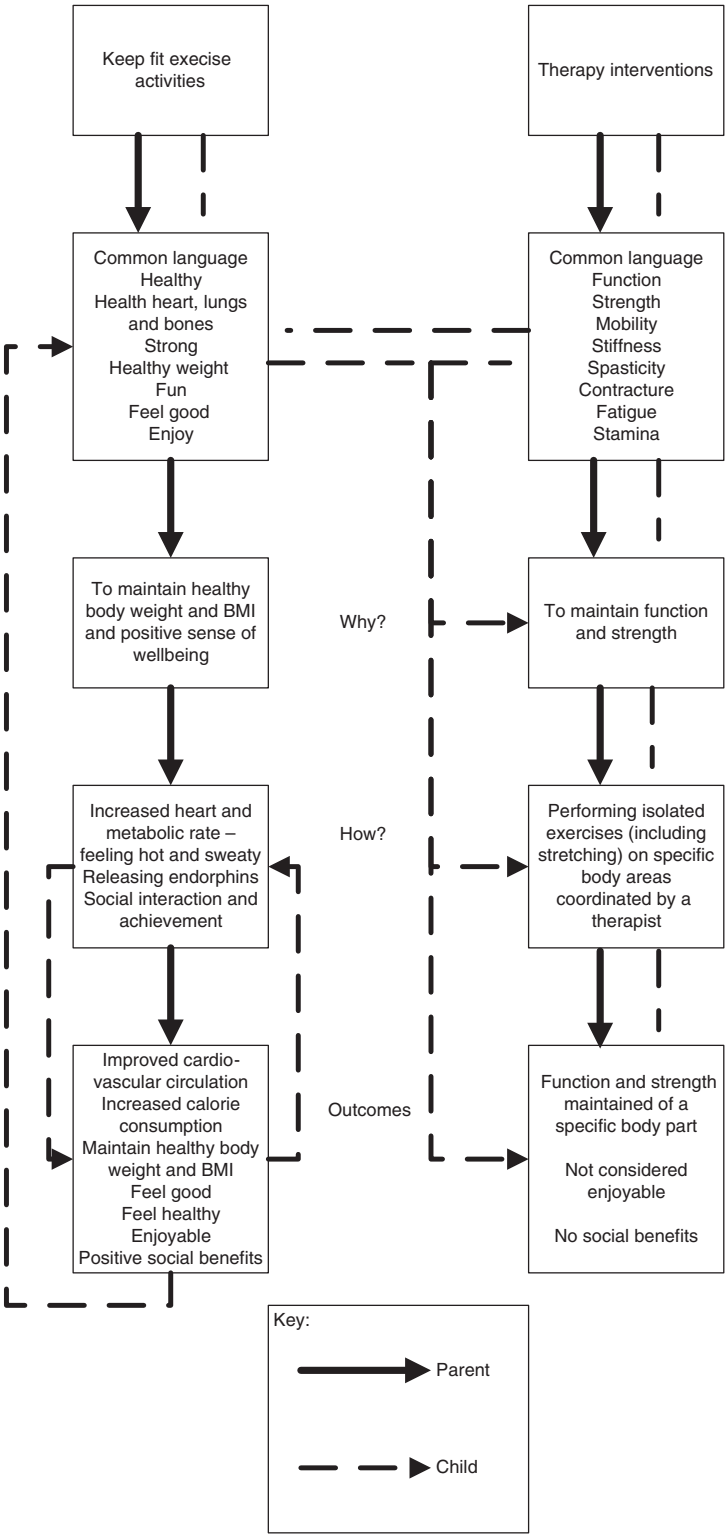

Figure 3 Parent and child conceptualizations of keep-fit exercise activities and therapy interventions.

done using body composition measurement with bioelectrical impedance analysis – a simple test to measure body fat. Body composition measurement should be made available for these children rather than requesting accessible scales and height sticks. Nurses will need additional training to do this routinely.

Although there has been investment to develop disability sports for children, there are fewer keep-fit activities available for children who use wheelchairs to use on a daily basis without the need for expensive special equipment or participating in a team or group activity (English Federation for Disability Sport no, date).

Strengths and limitations

One of the strength is the longitudinal engagement in data collection and gaining different child and adult perspectives on the same phenomena of interest.

Asking children and their families to self-select to participate in a study about their fitness had the effect of attracting those already participating in physical exercise and those who did not were very unlikely to respond. Around 60% of the sample had Cerebral Palsy, which mirrors other studies but does not represent the demographic of the total population of children who use wheelchairs. This evidence constitutes useful feasibility information to inform the design and recruitment strategies for future studies.

Conclusion

The general health and fitness of disabled children, especially those with mobility impairments, is not sufficiently acknowledged in policy or proactively monitored and addressed in practice. Proactive and physically active parents can go some way to compensate for the lack of health promotion support and advice and to overcome the considerable barriers, to enable their disabled children to engage in and benefit from physical exercise.

Introduction of body composition measurement is required into school health screening for children who need wheelchairs. PE lessons and teacher training need further improvement so more children engage in exercise. Misconceptions and misunderstandings of children about the differences between and benefits of therapy and physical exercise are likely to hinder their ability to better self-manage their health and weight as they grow up. Professionals (including nurses) need to improve the clarity of their communications to correct children's misunderstandings about the respective benefits of therapy and physical exercise. Further research is needed in this critically under researched area.

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Conflicts of interest

No conflict of interest was declared by the authors in relation to the study itself. Note that Jane Noyes is a JAN editor but, in line with usual practice, this paper was subjected to double blind peer review and was edited by another editor.

Author Contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (http://www.icmje.org/recommendations/)]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's web-site.

Data S1: Application of the Theory of Planned Behaviour (Azjen, 1991)

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