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Hotham, S., Hutton, E. and Hamilton-West, K.E. (2015) ***Development of a reliable, valid measure to assess parents' and teachers' understanding of postural care for children with physical disabilities: The (UKC-PostCarD) questionnaire.*** **Child: Care, Health and Development, 41 (6). pp. 1172-1178. ISSN 0305-1862.**

Abstract

Background: Previous research has highlighted a lack of knowledge, understanding and confidence among parents and teachers responsible for the postural care of children with a physical disability. Interventions designed to improve these qualities require a reliable and validated tool to assess pre and post intervention levels. Currently, however, no validated measure of postural care confidence (i.e. Self-efficacy) exists. Hence, the aim of this research was to develop a reliable and valid questionnaire to assess parents' and teachers' confidence, alongside knowledge and understanding of postural care– the *Understanding Knowledge and Confidence in providing POSTural CARe for children with Disabilities (UKC PostCarD) Questionnaire*.

Methods: Items were developed by a multidisciplinary team and designed to map onto the content of 'An A-to-Z of Postural Care' (Hutton et al., 2009). Parents, teachers and therapists assessed items for face validity; scale reliability was then assessed using Cronbach's alpha and known-groups validity was assessed by comparing scores of an 'expert' group (physiotherapists and occupational therapists) with those of a 'non-expert' group (with no formal training in postural care).

Results: The total scale and all three subscales (understanding-and-knowledge, confidence and concerns) demonstrated adequate reliability (α>.83) and subscale correlations formed a logical pattern (understanding-and-knowledge correlated positively with confidence and negatively with concerns). Experts' (N=111) scores were higher than non-experts' (N=79) for the total scale and all subscales (p<.001).

Conclusion: Findings support the reliability and validity of the UKC PostCarD questionnaire as a measure of understanding, knowledge and confidence in providing postural care for children with disabilities.

Introduction

The goal of therapy is to assist children with physical disability to fulfil their potential and participate in activities at school and home (Rodger & Ziviani, 2006). Impairment in a child's postural control, combined with environmental factors, influences the child's functional ability and can act as a barrier to participation (Coster et al., 2013; Hadders-Algra & Brogen- Carlberg, 2008; WHO 2007). A twenty four hour approach to managing the needs of a child with postural impairment, which may involve provision of assistive equipment and individualized therapy programs, is recommended to maintain functional ability and minimize longer term health problems (Gericke, 2006; Poutney, 2007; NICE, 2012). This approach requires knowledgeable, confident carers who are able to manage the care needs of children and make the appropriate adaptations to the child's everyday environment. Building capacity amongst carers to support the child at home and school is therefore an important element of an integrated and family centred approach (Stewart et al., 2006; Law et al., 2003; Jeglinsky, Autti-Rämö, & Brogren-Carlberg, 2012).

In the UK the majority of children with physical disability are educated in mainstream schools. A parents' choice to have their child educated within a mainstream school is a statutory requirement since the introduction of the Special Educational Needs and Disability Act (2001). The school environment presents particular challenges for children with disabilities, including a lack of knowledge and understanding of disability amongst teachers (Coster et al., 2013). While teacher training in the UK is attempting to address these shortfalls, the majority of teachers and teaching assistants (TAs) are inexperienced and untrained in how to meet the needs of children with physical disability (Nash & Norwich 2010; Devecchi et al., 2012).

Furthermore, qualitative research has highlighted a lack of comprehensive understanding of postural care amongst teaching staff in mainstream schools, undermining the child's inclusion (Hutton & Coxon, 2011) while consultation with parents revealed that information and practical support from therapists about how to implement postural care programs and use equipment varies (Hutton & Coxon, 2008). Recent policy, targeted at improving services for children with physical disabilities and their families, highlights the importance of providing information that supports the knowledge and skills of all those working with this population , alongside offering training to carers involved in delivering postural care strategies (Kennedy, 2010; NICE, 2012).

Aims and theoretical framework

In light of this research, we aimed to develop a questionnaire that could be used to assess information and training needs of those responsible for the day-to-day postural care of children with disabilities. It is intended that the questionnaire could be used as a tool to plan, deliver and evaluate postural care training for parents, teaching staff.

The questionnaire was developed on the basis of social cognitive theory (Bandura, 1989) which holds that people are more likely to expend effort to achieve their goals, and to persist in the face of obstacles, if they are high in 'self-efficacy'. The concept of self-efficacy corresponds to an individual's confidence in his or her own ability to carry out specific actions in a specific context (Bandura, 1977; 1997).

Consistent with this theoretical framework, we aimed to measure not only the individual's understanding (e.g. how postural care benefits the child's functional ability) and knowledge (e.g. in relation to postural care equipment), but also confidence in their ability to carrying out specific actions (e.g. moving a child safely) in a specific context (e.g. at home, in the classroom, or on a school trip). We also aimed to assess areas of concern in relation to providing postural care.

The questionnaire was designed to map on to the content of '*The A-to-Z of Postural Care'* (Hutton et al., 2009), a pocket-sized booklet developed with input from parents, therapists, researchers and educators. 'The A-to-Z' provides practical information and advice about postural care in an accessible format using simple language and illustrations. The content of 'The A-to-Z' is based on current good clinical practice guidance (NICE, 2012) underpinned by the International Classification of Functioning, Disability and Health – Children & Youth version (WHO, 2007) which highlights the dynamic interplay of impairment and environmental factors affecting participation. We aimed to take the same approach in developing the questionnaire.

Methods

Stakeholder involvement

An advisory group oversaw the management of the research. This group comprised NHS occupational therapists and physiotherapists, parents of children with physical disabilities, teachers, a disability advisor and academics (specializing in health services research, and health psychology). The group met at regular intervals and consulted on key topics (e.g., content of the questionnaire, potential recruitment strategies).

Questionnaire development

An initial list of items was developed to map onto the content of 'The A-to-Z'– these were divided into three sections 'understanding- and- knowledge of postural care' (e.g. 'I understand how to hoist safely'), 'confidence in applying the principles of postural care' (e.g.

‘I feel confident about providing postural care to a child with a disability’) and ‘concerns about providing postural care’ (e.g. ‘I am concerned that I might cause pain by moving a child into a different position’). A further section, relevant only to teachers, included items relating to postural care in the school environment and inclusion of disabled children across the school curriculum. Items designed to assess confidence in providing postural care in specific contexts (corresponding to the concept of ‘self-efficacy’) were developed following the guidelines provided by Weinman, Wright and Johnston (1995) – see Figure 1.

The advisory group was asked to review the list of items to assess face validity (whether items appear to measure the intended construct), identify redundant or ambiguous items, or suggest additional items (e.g. questions relating to specific school/home activities). Once a final list of items was agreed, a draft questionnaire was distributed to four NHS therapists and a specialist teacher. Their feedback helped to further refine the questionnaire in terms of phrasing, instructions and response format. Care was taken to ensure that the wording of the questionnaire was appropriate to the populations under consideration - avoiding technical terms and using language that would be familiar to both teachers and parents. Finally, in collaboration with the advisory group and the NHS therapists a definition of postural care to be included on the scale was also agreed (see box below).

Postural care is:
'The constant promotion of good posture to enable children to participate in all activities thus enabling them to fulfill their potential'

This resulted in the development of a 48-item questionnaire – the *Understanding Knowledge and Confidence in providing POSTural CARe for children with Disabilities (UKC PostCarD) questionnaire*. Further information about the structure and format of the questionnaire is provided in Figure 2.

Participants and Procedure

The sampling strategy was driven by the need to form two groups with different levels of experience and knowledge of postural care (in order to test 'known-groups' validity). This required the recruitment of an 'expert' group with formal specialized training in postural care (qualified occupational therapists and physiotherapists) and a 'non-expert' group with no formal training in postural care. It was important the non-expert group had sufficient knowledge to be able to answer questions about postural care; hence, we recruited parents[1] and teachers of disabled children.

Qualified occupational therapists and physiotherapists (*N* = 111) were recruited via adverts placed in newsletters for specialist sections within the United Kingdom College of Occupational Therapists (SS CYPF) and the Association of Paediatric Chartered Physiotherapists (APCP). Interested parties were directed to the School of Psychology electronic questionnaire management system (QMS2, University of Kent) where they provided informed consent and completed the questionnaire online. In addition, a link to the online questionnaire was placed on a discussion board of a specialist website which acts as online resource for professionals and others interested in postural care (http://www.posture24.com/).

Teachers and TAs (*N*=71) were recruited via local therapy teams in Kent, Surrey and Sussex, who identified schools with at least one physically disabled child. Invitation letters were sent to head teachers requesting the participation of teaching staff. Parents of children with physical disabilities were also identified via local therapy teams. In addition, eight parents and teachers completed the questionnaire online when posted on www.posture24.com. These participants were included in the 'non-expert' group. Hence, in

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[1] We recognise that parents have expert knowledge in the care of their own child but for the purpose of this analysis we include this group in the 'non-expert' group as they have received no *formal* training in postural care.

total, *N*= 79 non-experts completed either a paper or online version of the questionnaire. Participant characteristics are described in Table 1.

Participants also responded to open-ended questions enquiring about factors influencing the provision of postural care for children with disabilities and demand for training. Therapists were asked two open ended questions - ‘Can you think of anything else that would make it difficult for you to provide postural care to a child?’; ‘Can you think of anything else that would make it easier for you to provide postural care to a child?’. Parents were asked ‘Do you feel you would benefit from further information and/or training in relation to any specific aspects of postural care?’.

As an incentive, all participants were offered the chance to enter a prize draw to win one of two £25 gift vouchers. Ethical approval for the study was gained from the School of Psychology, Research Ethics Committee University of Kent and the NHS Research Ethics committee, South East Coast-Kent (11/LO/0653). R&D approval was provided by each of the NHS sites. Participants were treated in accordance with ethical guidelines issued by the University of Kent and the British Psychological Society (2009).

Design and data analysis

A cross-sectional correlational design was employed to examine the reliability of the scale (Cronbach’s alpha). We examined inter-correlations between the three subscales to check these followed a logical pattern, such that understanding-and-knowledge correlated positively with confidence and negatively with concerns.

For known-groups validity, a between-participants multivariate analysis of variance (MANOVA) was conducted, comparing mean scores for the two groups (expert vs. non-expert) across the three subscales (understanding-and-knowledge, confidence and concerns).A content analysis technique (Heiman, 1998) was used to analyze participants’ responses to the open-ended questions.

Results

Reliability analysis

Reliability for the total scale and the three subscales is reported in Table 2, alongside descriptive statistics. Cronbach's alpha > .70 was obtained for the total scale and for all three subscales, indicating adequate internal consistency (Nunnally & Bernstein, 1994). Furthermore, all item-total correlations for each subscale were >.30, further emphasizing the reliability of each subscale. The sections within each subscale also demonstrated adequate internal consistency (see Table 2).

Correlation analyses

Correlations between the three subscales formed a logical pattern such that understanding-and-knowledge correlated positively with confidence (r_s = .54, p<.001); concerns correlated negatively with both understanding-and-knowledge (r_s = -.39, p<.001) and confidence (r_s= -.51, p<.001). For participants in the expert group, number of years' experience correlated positively with understanding-and-knowledge (r_s =.32, p<.001) and confidence (r_s =.37, p<.001) and negatively with concerns (r_s = -.18, p<.05).

Known-groups validity

A MANOVA comparing scores on the three subscales in the expert vs. non-expert group revealed significantly higher levels of understanding-and-knowledge in the expert group (*M* = 3.30, *SD* = .39) than the non-expert group (*M* = 2.38, *SD* = .42), *F* (1, 188) = 237.15, p<001, η^2_p = .56.Compared to non-experts (*M* = 2.61, *SD* = .56), experts (*M* = 3.57, *SD* = .48) also reported higher levels of confidence, *F* (1, 188) = 160.24, p<001, η^2_p = .46.

Finally, lower levels of concerns were observed in the expert group (*M* = 2.14, *SD* = .56) compared to the non-expert group, (*M* = 2.63, *SD* = .52), *F* (1, 188) = 38.34, *p*<001, η^2_p = .17.[2]

Therapists' responses to open-ended questions

Eighty-six therapists provided a response to the open-ended questions. These responses were read carefully by the first author [SH]. Themes were labeled and sections of text corresponding to each theme were highlighted. The unitized sections of text were then provided to the second [EH] and third authors [KHW] in an Excel file. Changes were made to the categorization of the sections of text and to the labels provided until a final list of themes were agreed by all authors. This resulted in a list of four themes representing factors making it easier/more difficult to provide postural care.

The most prevalent theme was 'time and resources' (f = 54). For example, one participant wrote that "time to complete a proper assessment is vital", while another suggested that a "shared equipment store across health, social care and education would reduce a lot of waste and provide prompt solutions to needs".

The second most common theme was labeled 'consensus and co-operation', (f = 51). Responses linked to this theme highlighted a need for "joint working between health and social care and schools" and "closer working with medical teams such as surgeons, orthotists". Participants reported that postural care was more difficult when there is a "lack of cooperation with the postural care plan, aims and objectives from parents and others involved in the care".

A third theme was labeled 'understanding and knowledge' (f=9). Participants highlighted the importance of "parents having prior knowledge of types of equipment and the

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[2] As noted in Table 1, a significant difference in age between the expert and non-expert group was observed. In light of this, the same analysis was run with age as a covariate. Results from the MANCOVA did not differ from the original analysis- significant differences for all three variables were still noted between the expert and non-expert groups (all *ps* <.001).

long term effects of not adopting postural management equipment” and the need for “the team around the child to be fully aware of the postural care needs and willing to support them”.

The final theme (f = 5) highlighted the need for ‘access to training’ – for example, one participant wrote that it would be easier to provide postural care “if everyone in the medical profession, education, respite placements and parents had access to good training on the importance and benefits of postural care and ways to consider and respect the individual child’s needs”.

Parents’ and teachers’ responses to open-ended questions

In the non-expert group, 50 participants provided responses to the open-ended question. The majority indicated that they would benefit from further training (37 teaching staff, 13 parents). Two themes were strongly represented. The first related to a need for more training on equipment (f=19) - for example, one participant highlighted that “equipment is frequently updated therefore training would be beneficial to go alongside these changes”. The second theme related to information about providing postural care (f= 15) - for example, one participant indicated “I feel that knowledge of how to help with postural difficulties is very limited and therefore any input would be beneficial for my confidence”.

Discussion

This manuscript describes the development and validation of a questionnaire to measure understanding, knowledge and confidence in providing postural care for a child with a physical disability. Analyses indicate that the questionnaire and its three subscales are reliable and that correlations between these scales are in the direction expected. Known-groups validity analysis also revealed the expected results - specifically, individuals with specialist training in providing postural care reported significantly higher levels of understanding-and-knowledge and confidence, and lower levels of concerns than a group without specialist training.

A particular strength of the UKC PostCarD questionnaire is that items were developed on the basis of previous research with input from those who regularly care for, and work with, children with disabilities. The involvement of parents and teachers is in accordance with the shift towards patient and user involvement in the evaluation of health care interventions and development of questionnaires (Fitzpatrick et al., 2006). A second strength of the measure is the inclusion of questions that assess parents’ and teachers’ self-efficacy in relation to providing postural care. Previous research has consistently highlighted the role of self-efficacy in determining engagement in health-related behaviors as well as persistence in the face of obstacles (Bandura, 2006).Although understanding and knowledge is important, it is unlikely to be sufficient if the individual does not feel confident in their ability to apply this knowledge in the ‘real world’; hence, training packages need to go beyond simply conveying information and support participants to develop personal efficacy. The next phase of this program of research will use the UKC PostCarD questionnaire to evaluate such a training package.

The qualitative data collected in this study provides a useful insight into the challenges faced by those providing postural care in the school or home environment. Responses highlighted the need for sufficient time and resources (e.g. postural care equipment) as well as the importance of considering the entire team involved in caring for the child – a lack of understanding and knowledge in one part of this team can have implications for the ability of others to provide effective support. It is essential therefore that all members of the team have access to appropriate training and that the team is able to work together effectively to best support the needs of the child.

Although the questionnaire provides a reliable and valid measure to evaluate the postural care training package, there are some outstanding issues requiring further research. For example, we are mindful that the questionnaire was developed to evaluate changes in knowledge, understanding and confidence as a consequence of a targeted training program developed by the research team. Hence, it would be beneficial if future research could identify whether the questionnaire is a useful tool outside of this training program- for example, exploring how clinicians could utilize the scale in their day-to-day practice. Alongside this, it may also be beneficial to shorten the existing questionnaire to reduce the length of time it takes to administer. Hence future research will explore the development a valid and reliable abbreviated version. Finally, the questionnaire was also targeted towards those who provide care to primary school aged children (5-11 years old); hence, it would be useful to explore the validity and reliability of the scale with younger (i.e., nursery) and/or older (i.e., secondary) children.

Conclusion

Findings support the reliability and validity of the UKC-PostCarD questionnaire as a measure of understanding, knowledge and confidence in relation to providing postural care for children *with a range of physical disabilities, where difficulties with postural control are a feature*. We encourage the use of this scale in future research to better understand (and respond to) the training needs of those responsible for the day-to-day postural care of children with disabilities.

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For information purposes, the UKC-PostCarD questionnaire can be accessed online at http://goo.gl/IcDv65. If you would like to use the questionnaire please contact the first author for permission.

Declaration of interest

The authors report no declarations of interest

Key Messages

(1) Building capacity amongst carers to support the child with physical impairment is an important aspect of an integrated and family centred approach when providing postural care.

(2) This validated questionnaire was designed to evaluate a postural care training programme for parents and teachers of children with physical disabilities.

(3) A particular strength of the measure described in the article was the involvement of those who care for and work with children with disabilities on a regular basis, including parents and teachers.

(4) We encourage the use of the questionnaire by researchers and practitioners to better understand and respond to the training needs of those responsible for the day to day postural care for children with impairment.

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