

SUMMARY OF FINAL REPORT

An investigation of the effects of Dynamic Lycra Orthoses (DLOs) in the management of movement control problems caused by cerebellar ataxia

Principal researchers: Martin Watson, Kath Mares, Margaret McArthur, Paul Worth, Stephanie Brown, School of Allied Health Professions, University of East Anglia, Norwich, UK

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Background and aims:

Dynamic lycra orthoses (DLOs) are tailored garments, usually in this instance fashioned as shorts or leggings. They are made from a snug-fitting elasticated textile and are worn next to the skin. There is growing evidence that these garments can help to improve function in people who have a variety of movement control problems caused by damage to the central nervous system. The aim of this project was to evaluate their effect in the management of cerebellar ataxia (CA). Participants were assessed over an 18 week period and wore the garments for the middle six weeks of this time. Assessment of the effects of the DLOs was done by:

1. measuring changes in the functional performance of people wearing DLOs
2. exploring the experiences of people wearing DLOs and their perceptions of the garments

Results:

1. Evaluation of changes in functional performance as a result of DLO wear

Six study participants were monitored over the 18 week period with a number of quantitative assessment tools, to identify changes in performance which might be occurring as a result of DLO wear.

In terms of walking ability, energy efficiency whilst moving and balance and steadiness whilst standing, most participants appeared to show some improvements during the period of DLO wear. Additionally, after the 6 week period of DLO wear, most of these improvements were lost. However, only a small proportion of these changes were statistically significant.

Assessment of the participants' ability to get up out of a chair showed minimal, if any, change with DLO wear. Assessment of the function and neurological status of participants (using the International Cooperative Ataxia Rating Scale; ICARS), suggested some small changes in performance across the study period for each

individual. It was however difficult to identify changes which were coincident with introduction or withdrawal of the intervention.

Finally, participants were able to score their perceived performance changes in self-identified areas of everyday functional activity such as “coping with crowds”, “mobility”, “bathing and dressing”, “balancing in the shower” and “walking. Overall, the findings from this assessment were mixed. Of the 5 participants who completed this part of the study, 2 indicated increased satisfaction with their indicated areas of function, 2 showed the reverse and the fifth indicated little change in self-rated performance throughout the duration of the study. Overall these results appeared inconclusive, although 2 subjects perceived that they had benefitted in areas of function as a result of DLO wear.

Overall, the results of these quantitative evaluations were mixed. There appeared to be cautiously positive results in some areas of assessment for varying proportions of participants. It was evident that DLOs were able to influence some aspects of function. Large variability in physical performance in many participants, irrespective of DLO wear, appeared to be a common feature, complicating analysis. Overall, the study has shown that DLOs can positively influence certain aspects of everyday functional movement in some individuals; i.e. a proof-of-principle has been established

2. Exploration of the experience of people with CA and the use of DLOs

This part of the project used interviews to assess the participants’ experiences of living with CA and their experiences of wearing DLOs. Each participant was interviewed twice. The first interview focussed on movement problems that participants were currently experiencing and how these influence their daily life. The second interview reflected back on the issues raised at the first and took place after the six week period of DLO wear, allowing participants to comment on their experience of DLOs.

Emergent themes include falling, the loss of occupational performance, the loss of certainty for the future, the impact of societal perceptions and the challenges of coping. The respondents represented their lived experience of cerebellar ataxia as constantly evolving challenges to their physical, psychological and social welfare. This had an impact on not only themselves but also to the people who were significant to them.

The participants’ experiences of DLO wear are summarised below:

Perceived functional benefit

The fact that these people volunteered their involvement in this project indicates that they may have had some hope that the lycra garment would improve their function. The hope for improvement was confirmed during conversations with the respondents and the respondents’ significant others. There was a subjective judgment that four of the six respondents had made functional improvement during the period of DLO wear

Continued use of DLO

Despite the fact that four of the six respondents felt they had benefitted from the DLO, only one respondent liked wearing the garment and definitely intended to continue wearing the garment at the end of the project. Three other respondents specifically said that they did not like wearing the garment and would not wear it at the end of the project.

Fit and design

This was a recurring issue identified by all respondents and is the main reason why the majority of respondents would not be prepared to continue wearing the DLO. The garments were found to be hot and itchy. The perceived inaccessible location and difficult operation of the zip along with the tightness of the garment caused discomfort and also created significant problems with donning and doffing the garments. In addition, while DLOs are ostensibly constructed to facilitate toileting without the need for garment removal the respondents felt that the design did not allow them to use the toilet while wearing the garment. The difficulties with donning and doffing the garment therefore compounded the problem with toileting.

The perceived benefits of wearing the DLO were therefore overshadowed by the fit and design problems encountered by the respondents.

Benefits to people with ataxia arisen/likely to arise from this research:

This project presents cautiously positive results regarding the functional benefits of wearing DLOs for some people who have CA. Based on this small exploratory study, as well as some anecdotal evidence which is now emerging, one could probably justify prescribing a DLO to someone with movement control problems as a result of CA, although the effects will likely vary from person to person.

Publications arisen from this project:

We are currently developing the dissemination of the findings of this project. Our initial intentions are to produce:

- A publication detailing the effects of the DLOs on functional performance
- A report publication discussing the lived experience of the people with CA who participated in the study, including reflections on their experiences of wearing DLOs
- A structured literature review of the effects of DLOs in people who have CA and/or other movement/postural control problems

Conferences/ meetings where this research has been presented:

So far, this work has had restricted presentation, pending the completion of the final draft of the research associate's postgraduate thesis. Aspects of some of the quantitative results have been presented to two different regional groups, these being:

- StaR (Stroke and Rehabilitation) Forum, a university based forum of regional researchers and clinicians interested in neurological rehabilitation

- East Anglian regional meeting of ACPIN (Association of Chartered Physiotherapists Interested in Neurology)

The purpose of both of these presentations has been to obtain broader impressions of the project's initial results in order to facilitate further analysis and interpretation.

It is anticipated that wider dissemination of the study's results will occur during 2009-2010. Possible conferences that will be targeted are:

- National meeting of the Society for Research in Rehabilitation
- National Conference of the Chartered Society of Physiotherapy
- National Conference of the College of Occupational Therapists
- Ataxia UK conference

For more support or information please contact: Ataxia UK, Lincoln House, Kennington Park, 1 – 3 Brixton Road. London SW9 6DE

Website: www.ataxia.org.uk.

Helpline: 0845 644 0606 **Tel:** +44 (0)20 7582 1444 **Fax:** +44 (0)20 7582 9444

Email: helpline@ataxia.org.uk