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## BACKGROUND

Chronic pain and fatigue in the shoulder girdle and upper and lower back are significant and disabling symptoms in persons with FSHD.

Short boleros and prefabricated orthoses have been used to improve function and reduce pain, but randomly and with no systematic reporting of effect.

The aim of the study was to assess whether a customized, long DMO vest can reduce pain and fatigue in persons with FSHD, and to gather information on its usefulness, tolerance and comfort when used in daily activities.

## CONCLUSION

The DMO orthosis did not reduce pain and fatigue but the persons reported a positive effect on upper limb activities, and pain interfered less with activities of daily living after implementation.

An orthosis must be customized individually. It takes several adjustments to fit the orthosis and it is not suitable for all activities. Persons may be at risk of weak muscle overload due to the retraction of their shoulders and realignment of upper trunk position.

## METHODS

Eleven ambulant persons with FSHD (20-40 y) with regular pain in shoulder girdle, able to raise a glass of water to mouth (Brooke-UL score ≤ 3) and motivated for an orthosis were invited to participate in the study.

At time of inclusion persons were assessed by Brooke-UL score and manual muscle test (MMT) of shoulder and abdominal muscles. MRC score was calculated as a percentage of maximal possible score.

Persons filled in questionnaires on pain (Brief Pain Inventory - BPI), fatigue (Checklist of individual strength - CIS) and upper limb activities (Disabilities of the Arm, Shoulder and Hand - DASH) before and after the eight-week study period.

BPI rates the degree of pain severity (four items) and pain interference in daily activities (seven items) on a 0-10 scale. CIS quantifies subjective fatigue and related behavioural consequences of fatigue by 20 statements on a 1-7 scale. DASH rates difficulty and interference with daily life in persons with one or more upper musculoskeletal disorder by 30 items on a 0-5-point scale.

An orthotic engineer customized a DMO vest to each patient. After ten weeks, persons were interviewed about its effect and usefulness.

Differences in perception of pain, fatigue and upper limb activities were calculated by Wilcoxon signed-rank test.

## RESULTS

All 11 persons accepted the invitation (mean age 31.7 y). Three persons dropped out, one due to unsuccessful fitting of the orthosis.

Median Brooke score was 3 (1-3), MRC% in shoulder muscles was 61% (43-92). Weakest muscles were serratus anterior, trapezius 2 and 3, and the abdominal muscles (Fig 1). Most persons were weaker in the dominant arm.

Pain scores were high before and after the intervention ( $p=0.61$ ). Pain interfered less after implementation of the orthosis ( $p=0.012$ ). Mean scores before and after intervention are illustrated in Table 1. All persons reported pain in the shoulder girdle; some reported that pain was postponed, and they were more aware of when pain occurred.

Fatigue was reported as severe or heightened by all persons before the intervention. Although fatigue tended to decrease after intervention this was not significant (Fig 2).

The orthosis was used for work and spare time activities for an average of four hours per day (0-9 h). Persons reported fewer difficulties with activities of daily living after the intervention as measured by DASH ( $p=0.012$ ).

In general, the orthosis was used for sedentary activities such as driving a car and computer work; it was too warm for physical activities. One person – a house painter – felt massive pain after a few days' use because the retraction of shoulders led to an overuse of the very weak shoulder muscles.

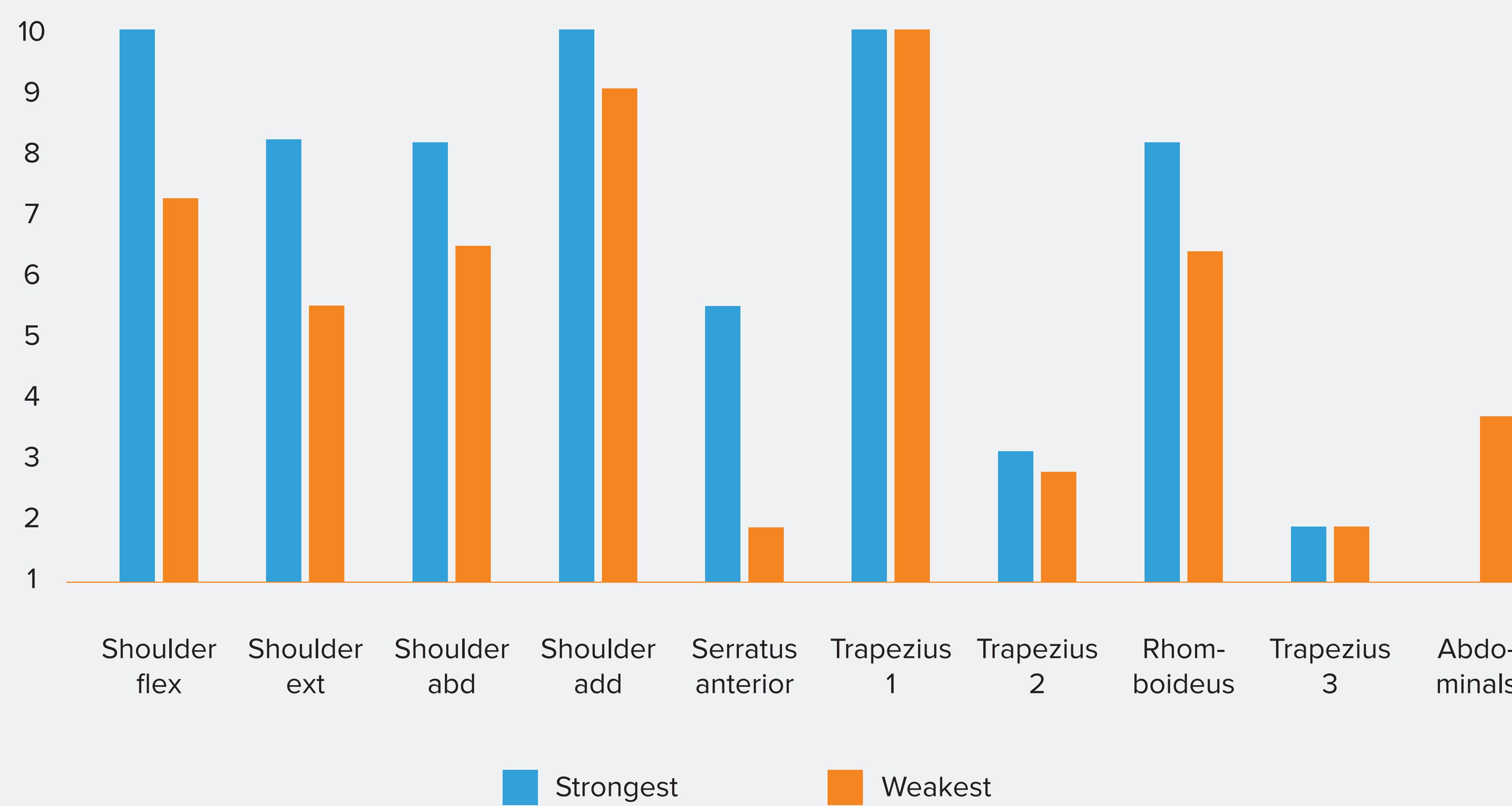


FIG. 1 MANUEL MUSCLE TEST (MRC) (N=11)

## FITTING

The orthosis was easy to put on, but very tight-fitting and all participants felt discomfort and pressure from seams in the arm pit, especially when moving their arms forward. Several adjustments were needed before the orthosis was comfortable.

Some female participants felt discomfort from the seams in the bra area.

## DESIGN OF THE ORTHOSIS

The vests were made of Lycra and had the same type of reinforcement – broad x-shaped paneling across the thoracic part of the back offering bilateral covering of the shoulder blade. Vests for persons whose stability in one shoulder blade was markedly different from the other were made with an extra layer of reinforcement over the most affected shoulder blade. All vests were made with x-shaped reinforcement paneling across the abdomen.

The aim of the reinforcement paneling was to retract the shoulders thereby realigning the sagittal plane. In the abdominal region, the aim of the reinforcement was to give outside support to weak abdominal muscles.

DM Orthotics Ltd funded the orthoses.



Items	Before (n=11)	After (n=8)
General activities	6.5	4.4
Mood	6.9	4.6
Walking	4.4	3.0
Work	6.5	4.5
Relations with others	4.8	3.1
Sleep	4.3	2.4
Enjoyment of life	3.9	2.4
Total	5.3	3.5

TABLE 1 PAIN INTERFERENCE (BPI) MEAN SCORES.

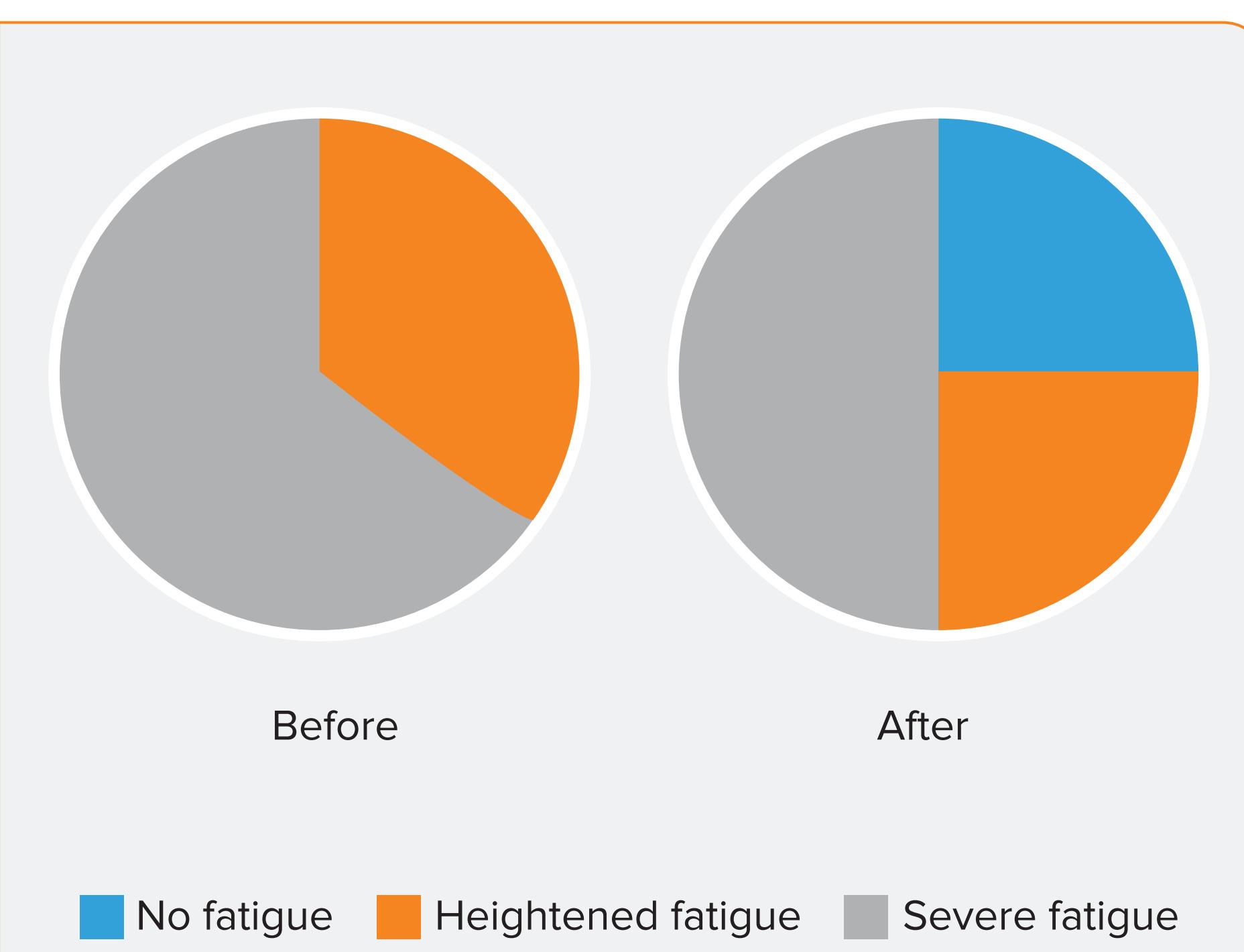


FIG. 2 CIS-FATIGUE (CIS8R), BEFORE AND AFTER INTERVENTION IN PERSONS (N=8) THAT COMPLETED THE STUDY.