

BOOST: A Self-Management Programme for People with Multiple Sclerosis

Pearce, L. (Occupational Therapist), Gaskell, H. (Physiotherapist) & Rogers C. L. (Clinical Psychologist)
Oxford Centre for Enablement (OCE)

Introduction:

- Supported self-management for people with long term health conditions is being used nationally to increase patient knowledge, skills, and self-efficacy to maintain their best health, achieve personal goals, and improve quality of life. It has been suggested that pro-active supported self-management can enhance healthcare outcomes and reduce health- and social-care burden (De Silva, 2011).
- People with Multiple Sclerosis (MS) manage their symptoms and the changes to functioning on a day-to-day basis with intermittent input from health care professionals, but there is no consensus of the most effective way to deliver support for self-management or review outcomes (De longh et al, 2015).

References:

De Silva, D. (2011) Helping people to help themselves: A review of the evidence considering whether it is worthwhile to support self-management. The Health Foundation.
De longh, Fagan, Fenner & Kidd (2015) A Practical Guide to Self Management Support. The Health Foundation.

Background Information:

- The programme was originally created in 2013 to meet the needs of people referred to the service who did not need or want to attend the standard day hospital programme; i.e. still working or leading active lives, earlier in the disease process and fewer impairments.
- This was offered to patients with any long term neurological conditions.
- The majority of participants were found to have MS and this had been the focus of group member led discussions. Feedback was that other participants felt less included.
- In 2017 it was relaunched as an MS programme to meet the specific needs of this client group.
- The name 'BOOST' was chosen to reflect the aim of the programme - to positively BOOST people's existing self-management skills.
- The screening process was changed from telephone screens to face-to-face screening to ensure appropriate attendees were invited and encourage high attendance rates.

Programme Information January-March 2018 programme:

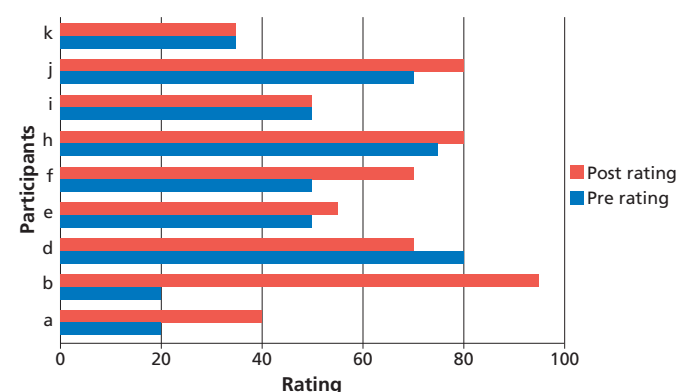
Programme Aims

- To promote a sense of self-management and control over symptoms.
- To facilitate adjustments through peer support and the sharing of experiences in the group.
- To provide information on strategies and resources to maximize knowledge and independence.
 - Referral criteria:** People with MS with an Expanded Disability Status Scale (EDSS) score of 6 or above, leading independent and active lives.
 - Screening:** 25 people were offered face to face screening appointments in order to identify 10 participants who met the referral criteria and wanted to attend. Those not invited were offered other services if appropriate.
 - Professionals involved** – Occupational Therapy, Clinical Neuro-Psychology, Physiotherapy, Continence Advisory Nurse, MS Specialist Nurse, Neuro-Rehabilitation Consultant, Speech and Language Therapy

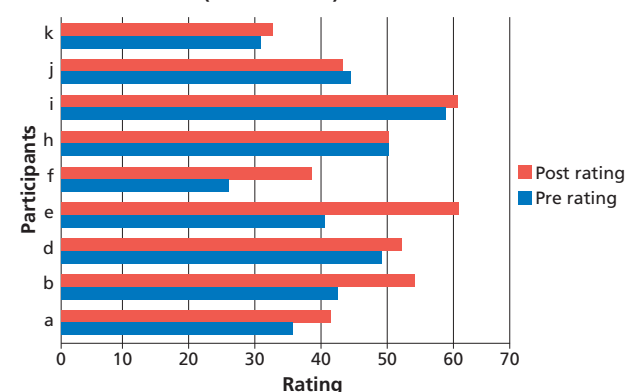
2018 Boost Programme outcomes

Group participants completed the following pre- and post- group measures:

Wellbeing Glass Outcome



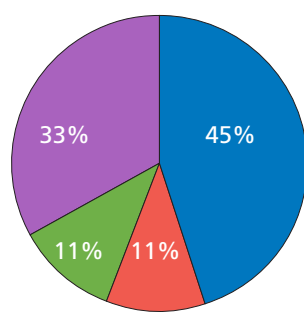
Warwick Edinburgh Mental Well Being Scale (WEMWBS) Outcomes



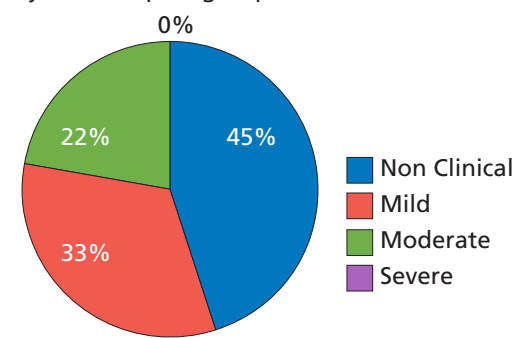
- On the Wellbeing Glass, the majority of participants demonstrated improvement in their perceptions of their health & wellbeing. Pre-ratings ranged from 20-80, whilst post-ratings ranged from 35-95. The average difference was 14, whilst one participant's rating increased by 75 points.
- On the WEMWBS, group data indicated an improvement between pre-ratings (M= 42.6; R = 26-50) and post-ratings (M=49; R=33-62), with three participants showing significant improvement in their mental wellbeing (a score difference of 9.70), indicating significant reliable change (1.96 +/-). No participants mental wellbeing scores significantly declined.

Hospital Anxiety and Depression Scale (HADS) outcomes

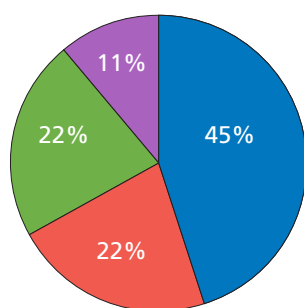
Anxiety subscale pre-group outcomes



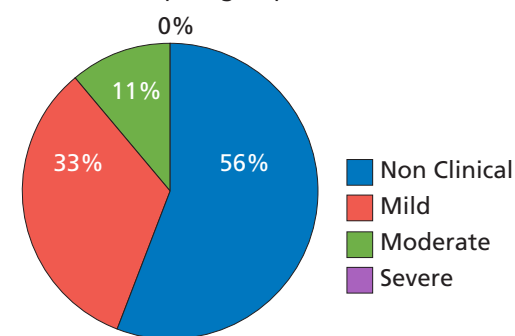
Anxiety subscale post-group outcomes



Depression subscale pre-group outcomes



Depression subscale post-group outcomes



- Group data demonstrated improvements in pre-ratings of anxiety (M= 9.9, R=3-17) compared to post-ratings (M=7, R=0-13); and pre-ratings of depression (M=8.8, R=3-16) compared to post-ratings (M=6.4, R=2-13). After the programme no participants self-reported in the severe range.
- Wilcoxon matched-pairs Signed-Rank test indicated a significant difference between pre and post measures of anxiety (V=26, p = 0.02); but was non-significant for the measure of depression.
- On 5-point Likert-scale measures constructed for the programme, the majority of participants reported they "agree" (4): they understood MS, felt confident in managing symptoms, could manage setbacks, felt in control or their condition, and had awareness of services and where to seek support.

2018 Boost Programme:

| | Week 1 | Week 2 | Week 3 | Week 4 | Week 5 | Week 6 |
|---------------|-------------------------------------|--|---|--|--|---|
| 10.00 - 11.15 | Welcome, Introduction Relaxation | Managing Medical issues & Medication | Managing Emotions | Communication & swallow | Managing Intimate relationships | What next? Future Goals Relaxation |
| 11.15 | Break | | | | | |
| 11.30 | Physiotherapy Exercise Talk | Physiotherapy Exercise Session • Pilates | Physiotherapy Exercise Session • Aerobic | Physiotherapy Exercise Sessio • Balance | Physiotherapy Exercise Session • Strength | Physiotherapy Exercise Session • Flexibility |
| 12.15 - 13.00 | Managing Fatigue | Information Sharing & Benefits Relaxation | Bladder & Bowel Management | Relaxation | Relaxation | Outcome measures & evaluation |

Reflections:

- Improvements in the majority of pre and post outcomes measures.
- Positive verbal and written feedback.
- Large increase in referrals from MS Specialist Nurses, due to greater awareness of the programme and outcomes which have demonstrated the positive gains made by participants.
- Improved attendance with face-to-face screening.
- High group cohesion and members commented on the value of peer support (both emotional and practical) that the group provided.
- Active involvement in the sessions.

Future plans:

- Continue face-to-face screening.
- Increased emphasis on goal setting at start and throughout the programme – with a goals review in each session.
- Inclusion of sessions on memory/cognition, and diet/nutrition, following feedback from participants.
- Programme to extend to seven weeks and to run twice-yearly.
- Consider running a family session and follow up day in future

Qualitative Feedback:

When asked about what they had found most helpful about the programme, participants commented:

'Meeting other people with the same condition'

'Finding the courage to talk to other people'

'Knowing that I'm not alone with MS'

'Sharing ideas and knowing what other people are doing'

'I have learned new things and things I already knew I have been reminded of and have started to implement'

'Sharing knowledge and developing dialogue'

'I feel like I have gained confidence and drawn from the positivity of others'

'The laughter was a release'

'Professional advice on managing MS'

'Thinking and taking time to think'