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Wellness Enhancement Learning

An Evaluation of The WEL for CFS/ME

Evaluation Report on Developing a Model of Care In Long Term Conditions

using a Wellness Enhancement Learning Programme,

Piloted for People with CFS/ME Chronic Fatigue Syndrome

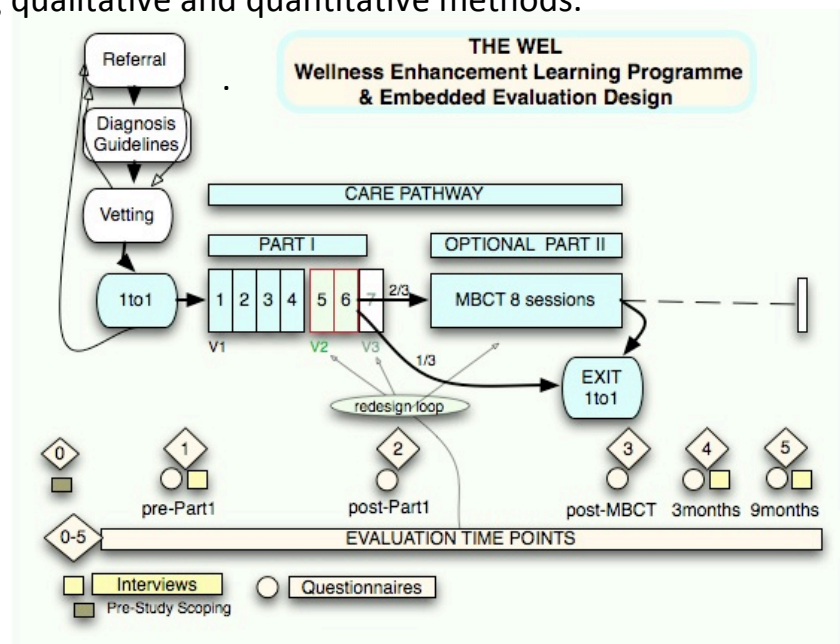
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Evolving a Model of Service Development & Evaluation in Long Term Conditions

Built on User's Experiences and Assessments

using an Embedded Learning and Redesign Loop,

blending qualitative and quantitative methods.



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ABSTRACT

AIMS

This is an evaluation of a project with two main aims: 1) To develop and assess new approaches for helping people with long term conditions using a wellness enhancement learning programme – The WEL, in a version tailored for people with CFS/ME; and 2) To help improve ways of assessing care - by using patient-centred outcomes, mixing quantitative and qualitative measures, and then using this to evolve the service design with an ongoing learning loop.

THE MODEL OF CARE

The report covers the developmental phase in The Centre for Integrative Care, Glasgow Homoeopathic Hospital between 2005 and 2007. The programme contains practical elements such as meditation, mindfulness and cognitive skills; and self-care information - for example on nutrition, and regulating cycles of sleep and physical activity. However the essential core process underlying this is supporting the person in a self-enquiry developing awareness around their self-care and self-compassion - which the programme suggests underpin the process of achieving changing self-care and self-management and then sustaining improvement over the longer term.

The Part 1 course was designed afresh from experienced clinician's practice (4, later 7, weekly half day sessions with backup home-use and web materials), the Part 2 was a modified version of MBCT Mindfulness Based Cognitive Therapy (over 8 weekly half days).

EVALUATION METHODS

The design was a prospective observational evaluation study combining qualitative and quantitative methods. Five established and validated health outcome measures designed to give an indication of health status and quality of life from a patient-centred perspective were used including one specifically standardised for CFS – these were: Fatigue Impact Scale; SF-12 recommended by the International CFS study group to provide information on general health status; ORIDL (Outcome Related to Impact on Daily Living); MYMOP (Measure Yourself Medical Outcome Profile); and PEI (Patient Enablement Instrument). The qualitative method was the biographical narrative interpretive methodology (BNIM), selected to allow patients to convey the meanings that they attribute to their experience of their illness, their past and present experiences of health care and other services, and any change that they experience during and after the intervention.

PARTICIPANTS

71 patients over 18 years of age (average 40, 17-69) were recruited in 5 cohorts at 4 months intervals, and evaluated during, after and at 3 month evaluation periods. 88% were referred by General Practitioners, 43% suggesting the referral themselves, 60% were unable to work due to ill health. 8 (11%) were not eligible for follow-up having dropped out in the first few weeks. Of the remaining 63 patients, 61 (97%) completed the post Part 1 WEL questionnaire, and 55 (90%) of these 61 completed the 3 month post WEL questionnaire. Of those entering The WEL, 43 (68%) opted to also do the MBCT training and all 43 (100%) fully completed MBCT and returned the post MBCT questionnaire. 40 (85% of a total possible of 47) completed the 9 month questionnaire (Cohort 5 being excluded because of too recent entry into the programme).

RESULTS

The baseline qualitative results gave a rich description of the significant personal and health care difficulties the patients had experienced in their journey up to this point, struggling in a system not yet geared to long term condition management and often not understanding their situations. The quantitative results then suggested sustained levels of enablement, and benefits in coping and wellbeing, and after a lag, symptoms, in most participants, rated as sufficient to enhance daily life in around half of participants, and statistically significant from early on in the course. These changes seem to have then continued to progress in the months following the course suggesting that the aim of self-sustaining growth of improved self-care and self-management, with resultant enhancement in wellbeing, was being achieved. In the cohort of 47 people followed up for 9 months, 70% of people report some continued improvement in their coping, 60% in their wellbeing and 55% in their symptoms, sufficient to change the quality of daily life in 50%, 47% & and 39% respectively. Qualitative results showed that while some people were challenged by the whole-person approach and the course practicalities, there was almost universal endorsement of The WEL model's group format, and staff and service ethos. People reported increased awareness and changed behaviours around self-regard and self-care, incorporated mindfulness and other new practices in daily life, and satisfaction in the group process. The people who derived most benefit report that they now want to make an impact on their own health and that the course provides the skills and strategies both to make a start on improving their wellbeing, and also plan a longer term journey of improvement.

DISCUSSION

Taken generally, these results suggest that helpful gains in health and wellbeing can be achieved by a wellness enhancement approach, and more specifically,

this can bring meaningful gains for people with CFS/ME. Combining qualitative and quantitative patient centered measures seems to give a fuller understanding of the outcome of care and offers a useful basis for future developments, especially when used in a learning-loop embedded in on-going service redesign. Future work could usefully evaluate the now iterated service model in CFS/ME; the parallel General version of the programme; and explore in more depth the process of change that people have described, and the conditions that support this.