A Pilot Study of the Process of Change in a Group Chronic Fatigue Syndrome Management Programme

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ABSTRACT

Background: Cognitive-behavioural therapy and graded exercise therapy are efficacious therapies in patients with Chronic Fatigue Syndrome (CFS). There is some evidence for the efficacy of group programmes that employ the same principles of rehabilitation. Little is known about the process of change with these interventions, however it is important to understand why change occurs in order to improve outcomes. Objectives: To investigate the process of change and related outcomes in participants in a CFS group management programme. Method: Task analysis was used to generate a health professionals’ model specifying the psychological shifts thought necessary for participants to improve. Following this, data from participant interviews were analysed to see whether they matched the shifts specified in the model. Results: Participants were able to identify ‘key moments’ which they thought were involved in change. One commonly cited key moment involved participants coming to the realization that they were not unique in their difficulties and there were others in the group who understood, and had experienced similar problems. Four of the six shifts identified by health professionals were also identified as key moments by participants. Conclusions: This study highlights the potential benefits of group work for people with CFS/ME including opportunities for validation from peers, sharing and modelling, all of which are suggested to be important in the process of change.

Key words: Chronic Fatigue Syndrome, group therapy, key moments, process of change, task analysis
INTRODUCTION

Chronic Fatigue Syndrome (CFS), or Myalgic Encephalomyelitis (ME), is characterised by disabling tiredness that is accompanied by a range of other symptoms (1, 2). A number of aetiological factors have been associated with the condition including immunological, genetic, viral, psychological and neuroendocrine (3,4). CFS/ME is a serious disorder that involves a considerable healthcare burden (3).

Bio-psychosocial models (5, 6, 7, & 8), have lead to the development of cognitive-behavioural interventions for the condition and there is evidence to support the use of both Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET) for CFS/ME (1,2, 9, & 10). CBT aims to help patients reassess their beliefs about the illness and learn better coping skills (11). GET aims to reverse physical de-conditioning, and exercise intolerance, by setting an achievable baseline of activity, followed by planned increases in duration and intensity of exercise, as well as goal setting and evidence-based explanations of symptoms (4). Pacing, an approach advocated by patient groups (12), aims to help patients match their activity level to the amount of energy they have in order to facilitate natural recovery (13). The first research trial to include this approach is currently underway in the UK (http://www.pacetrial.org/). None of these approaches to treatment are completely differentiated and research trials which refer to CBT for CFS/ME actually describe treatments which involve some degree of graded exercise and pacing within their approach. The UK Medical Research Council (MRC) has recommended that integrated treatment packages may be more beneficial than either CBT or GET alone (14).

There are a small number of studies which have investigated the efficacy of group CBT for CFS/ME (15-18). However, group interventions can be more cost effective and they make use of the powerful effects of group processes (11). There has been one recent randomised control trial that compared group CBT for CFS/ME with an Education and Support Group (EAS) and Standard Medical Care or SMC (15). Group CBT was effective in treating symptoms of fatigue, mood and physical fitness in CFS/ME. Group CBT was as effective as trials of individual therapy in these domains. Participants in the EAS group also showed improvements which, the authors suggested, indicated the value of the non-specific effects of therapy.

The process of change in psychotherapy

Gaining a better understanding of how a treatment programme works can aid identification of the active ingredients in therapy (19) and enable interventions to be altered in order to maximise the effectiveness of treatment. Process research attempts to identify the psychological processes that result in emotional, behavioural and psychological change during and/or following an intervention (19). Currently, there is little research into the process of change that occurs during treatment for CFS/ME. One study that looked at the ‘active ingredients’ in
counselling and CBT for patients with chronic fatigue, found that emotional processing was the key predictor of a good outcome (20). Emotional processing involved patients expressing emotion, disclosing thoughts and feelings, acknowledging and accepting their feelings, and working actively with the therapist’s comments. Another study of group therapy showed that patients with CFS/ME found the most helpful aspects of the treatment were being able to share experiences within the group and hearing the experiences of others with CFS/ME, as well as feeling that the other people in the group understood them and they were therefore ‘close’ to one another (21).

Factors which have been associated with therapeutic change in group psychotherapy, include installation of hope, universality, imparting information, altruism and imitative behaviour (22). In addition the literature suggests that certain non-specific factors, such as the therapeutic alliance, contribute significantly to change in individual therapy (23), and the development of self-efficacy has been found to be an important mechanism of change in self-management programmes for other chronic conditions such as arthritis (24). Overcoming avoidance would also appear to be an important factor in the change process for patients with CFS/ME as avoidance of activity due to fear can maintain patterns of behaviour in this condition (25).

**Studying change processes**

Process research often involves detailed analysis of individual sessions with particular patients but this limits its ability to be generalised to other patients (26). These studies frequently use independent observers’ perceptions of what occurs during therapeutic interactions, however the client’s own perceptions of significant events in therapy have also been used to identify the active ingredients in therapy (27).

Task analysis is one method of studying the process of change. Task analysis involves designing a hypothetical model of how a patient might achieve change in a given task or therapy, measuring how well this fits with real life, and then altering the model to bring it into line with what those measurements indicate (28). Initially the tasks thought to be required for the patient to change, (i.e. the psychological shifts necessary for change) are specified. This is then tested against patients’ experience of change. Task-analysis has been used to investigate the process of change in a group pain management programme, or PMP, (Ridout, 2003, unpublished data). In this study a group of health professionals constructed a hypothetical ‘expert’ model of change. In interviews conducted following the end of the group programme, participants were asked to identify “key moments” when they became aware of change in relation to themselves and their functioning. This data was then used to create a refined model of psychological shifts necessary for change.
The present study aimed to explore the processes by which change occurs in a group management programme for people with CFS/ME, using a methodology which partially replicated that of Ridout (2003, unpublished data). The impact of a CFS/ME group management programme on key outcome measures for participants with CFS/ME, was investigated using a pre- and post-group comparison. In addition to this the qualitative method of task analysis was used to identify the psychological shifts occurring during the group programme, according to a) health professionals, and b) participants.
METHOD

Participants

Twenty-three people with CFS/ME had been previously identified to attend the CFS/ME group management programme in the service where the study was conducted. They were randomly assigned to one of two groups, of 11 and 12 people each. The two groups followed the same programme and were run simultaneously. There were no major demographic differences between the two groups both of which contained people of a range of ages and a mix of male and female participants. Of these, 17 individuals, previously identified as appropriate through assessment by a specialist multi-professional clinical team, agreed to take part in the study. Of the 6 people who participated in the group but did not take part in the study, five declined to take part and one was not invited to take part due to the presence of a known co-morbid medical diagnosis. Participants had to fulfil the Oxford Criteria for CFS/ME (29). The exclusion criteria included a) a degree of disability that would prevent weekly attendance at an outpatient group, b) the presence of another disorder that might account for their symptoms, confirmed by GP, and based on the CDC report listing disorders that would exclude a diagnosis of CFS/ME (30), and c) the presence of a co-morbid psychiatric diagnosis (confirmed by GP).

In this study a 10-week CFS/ME management programme, which was run by a multidisciplinary team of psychologists, physiotherapists, and occupational therapists, used an integrative approach incorporating strategies from CBT, GET, and pacing. A previous service evaluation of this particular management programme showed significant improvements in a range of health outcomes post group and at follow-up. Participants were encouraged not to engage with other interventions (including medication and alternative therapies) whilst participating in the group management programme.

Procedures

Participants completed the standardised measures before the first group session and after the last group session. At the end of the group programme participants were interviewed by the first author (GR).

In the first stage of the task analysis four health professionals (two clinical psychologists, a nurse and occupational therapist, with considerable experience in research and management of CFS/ME) met to generate a hypothetical model of the psychological shifts presumed to underpin change in a group CFS/ME management programme. Evidence for the psychological shifts included in the model was based on the knowledge base of the health professionals and the literature on theoretical models of CFS/ME, pain management research, and psychotherapy change research. The first author (GR) was in the room when this took place but did not contribute to the process.
Measures

Standardised quantitative measures: Outcomes were assessed on standardized measures in a number of domains. The Fatigue Scale, (31) was used to measure physical and mental fatigue. This questionnaire has good reported internal consistency (Chronbach’s alpha calculated for each item ranged from 0.88 – 0.90), and construct, validity (31) and has been used extensively in CFS/ME research. Functional disability was assessed by the physical functioning subscale of the Medical Outcomes Survey Short-Form-36 or MOS SF-36 (32). This is a well-validated measure (Chronbach’s alpha of 0.90; 33) with considerable normative data available for both normal and clinical populations (30). The Work and Social Adjustment Scale or WSAS (34) was used to measure participation. Good reliability (e.g. test-retest correlation of 0.73 & Chronbach’s alpha of 0.70 – 0.94) and validity (e.g. correlations of 0.76 between the WSAS and severity of depression symptoms) has been demonstrated for the scale (35). Emotional distress was assessed using the SCL-90 R (36). There are norms available for this scale for functional/normal populations as well as populations with specific disorders including CFS/ME. Chronbach’s alpha coefficients ranging from 0.77 – 0.90 for the SCL-90 R have been reported (37). Quality of life was measured by the modified Patient Generated Index or PGI-R (38). Measuring internal consistency is not appropriate as each domain is separate and identified individually by patients (39), however, test-retest correlations of 0.7 over a two week period have been reported (38). Content validity is ensured by the fact that each individual patient specifies their own content (39). Other authors (40) have found that the PGI has acceptable reliability and validity.

Semi-structured interview: In partial replication of Ridout (2003, unpublished data), and following completion of the group programme, participants took part in a semi-structured interview. During this interview participants were asked to identify personal “key moments”, ‘when something “clicked” for you in terms of how to manage CFS/ME’.

Data analysis

Statistical analysis (a series of paired sample t-tests) was performed on the data received from the outcome measures, since all measures were normally distributed.

Analysis of transcripts of the semi-structured interviews

This was done in two stages. In stage one, two raters (a trainee psychologist and an assistant psychologist) identified key moments in each transcript. The first transcript to be rated was used as a pilot. After working on this first transcript the two raters met to discuss any discrepancies in their ratings. Key moments that could not be agreed upon were discarded. Following this the remaining transcripts were then analysed by both raters independently, who repeated the process carried
out in the pilot until an agreed set of key moments had been identified for each transcript. At stage two of the analysis, two more raters (an assistant psychologist and a qualified clinical psychologist) then coded each of the identified participant key moments into the six psychological shifts in the health professional’s model. Any shifts that could not be coded were to be placed apart and possibly allocated to a separate category. The index of agreement between raters was 85 %, however this did not reach statistical significance. Cohen’s Kappa was used to check the level of agreement between raters. A kappa value of 0.37 was found, where values between 0.40 and 0.60 have been suggested as indicative of a ‘fair’ level of agreement (41).

Credibility checks: A number of credibility checks recommended for qualitative studies (42) were used. An ‘analytical auditor’ was used in the form of the second author (a clinical psychologist with considerable experience in working with patients with CFS/ME). The first author (and stage one rater) met with the analytical auditor to review different key moments that had been identified from the transcripts. In addition, multiple analysts (one trainee psychologist, 2 assistant psychologists and one qualified psychologist) were used at both stages of the qualitative analysis (i.e. when identifying key moments from the transcripts and when categorising identified key moments into psychological shifts described in the model). Both the analytical auditor and the multiple analysts helped to ensure third-party verification of key moments and coded psychological shifts, and identify discrepancies, overstatements or errors. A reflective diary (i.e. a verbal narrative kept at various stages of the analysis including details such as evolving themes for key moments in transcripts) was kept by the first author to facilitate transparency. Triangulation of data was achieved through the use of data from multiple sources, i.e. both health professionals, and people with CFS/ME.

RESULTS

Description of participants Participant’s were between 18 and 58 years of age (mean 39). There were 6 males and 11 females.

Outcomes of the CFS/ME group management programme Comparison of group means (see Table 1) showed significant improvements in fatigue, (t= 3.801, df = 16, p< 0.05), and self-reported quality of life (as measured by the PGI-R), (t= -2.362, df = 15, p< 0.05).
Table 1

Table 1 Outcome data for participants on all measures and p values for paired sample t-tests comparing pre- and post- group data.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre-group Mean (SD)</th>
<th>Post-group Mean (SD)</th>
<th>P values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue Questionnaire</td>
<td>21.06 (6.38)</td>
<td>15.24 (7.91)</td>
<td>0.002*</td>
</tr>
<tr>
<td>MOS SF-36 (Physical Functioning Subscale)</td>
<td>50.33 (18.67)</td>
<td>53.67 (23.87)</td>
<td>0.420</td>
</tr>
<tr>
<td>Work &amp; Social Adjustment Scale</td>
<td>27.00 (7.87)</td>
<td>26.65 (8.46)</td>
<td>0.514</td>
</tr>
<tr>
<td>SCL-90 R Depression Scale</td>
<td>1.31 (0.97)</td>
<td>1.21 (0.90)</td>
<td>0.577</td>
</tr>
<tr>
<td>SCL-90 R Anxiety Scale</td>
<td>0.74 (0.93)</td>
<td>0.69 (0.82)</td>
<td>0.782</td>
</tr>
<tr>
<td>SCL-90 R Positive Symptom Distress Index (PSDI)</td>
<td>1.85 (0.51)</td>
<td>1.73 (0.55)</td>
<td>0.325</td>
</tr>
<tr>
<td>Modified Patient Generated Index (PGI)</td>
<td>2.69 (1.57)</td>
<td>3.49 (1.89)</td>
<td>0.032*</td>
</tr>
</tbody>
</table>

* p <0.05 on a paired samples t-test

Psychological shifts (health professionals) and Key Moments (participants) identified by a) health professionals, and b) participants. The qualitative analysis found that the psychological shifts identified in the health professionals’ model were broadly consistent with the key moments that participants perceived to have occurred during the CFS/ME group management programme. The health professionals’ model identified six psychological shifts, some or all of which were deemed necessary for improvement to occur during treatment. The results from the analysis of key moments and their coding into the psychological shifts in the health professionals model are shown in Table 2. Examples are given for the four psychological shifts that were found to have more than one key moment.
Table 2

Table 2 Coding of participant’s key moments into the psychological shifts in the health professional’s model.

<table>
<thead>
<tr>
<th>Shift</th>
<th>Number of participants 1 (n=17)</th>
<th>Number of key moments coded 2 (n=119)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Shift one</strong>: medical model - bio-psychosocial model</td>
<td>7</td>
<td>12</td>
</tr>
<tr>
<td><em>Example</em>: ‘...it was good in helping you sort of understand the illness. Um, which I think was the most helpful... so that you know you’re not just imagining it.’</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Shift two</strong>: fear avoidance – willing to try things/ experiment</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Shift three</strong>: helplessness, hopelessness, low self-esteem – in control, hopeful, high self-esteem</td>
<td>11</td>
<td>19</td>
</tr>
<tr>
<td><em>Example</em>: ‘I found the action planning quite helpful because it means that you had done something purposeful ...then you could ...work out what you have managed to do each week and that you were going forwards.’</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Shift four</strong>: extremes of thought, feeling, behaviour – more balanced thoughts, feelings and behaviour</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td><em>Example</em>: ‘Its basically....well, I am a perfectionist and won’t leave things half done, whereas now I do...if things...need doing they get left now, whereas before I would push myself to do things.’</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Shift five</strong>: feeling de-valued, self-critical - feeling valued and compassionate</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Shift six</strong>: feeling isolated/unique – feeling accepted, understood, similar</td>
<td>16</td>
<td>57</td>
</tr>
<tr>
<td><em>Example</em>: ‘When asked whether it was helpful to know he was not the only one with his kind of difficulties, one participant replied: ‘Yes, I mean that was a big thing for me because you suddenly didn’t feel alone.’</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No shift identified</td>
<td>8</td>
<td>16</td>
</tr>
</tbody>
</table>

1Number of participants who were found to have each shift.

2Number of key moments which were identified for each shift.
DISCUSSION

This study provides some evidence that an integrative group programme for people with CFS/ME, may be associated with improvements in key outcomes. Statistically significant improvements found for fatigue and quality of life, are consistent with the results of two recent studies of group programmes for CFS/ME (43, 15). Six psychological shifts were identified by experts using a task analysis method, namely: 1) medical model to a more bio-psychosocial model; 2) fear avoidance to a willingness to try things/experiment; 3) helplessness, hopelessness, low self-esteem, to in control, hopeful, high self-esteem; 4) from extreme, to more balanced, thoughts, feelings and behaviour; 5) feeling de-valued and self-critical to feeling valued and compassionate; and 6) feeling isolated and unique to feeling accepted, understood and similar. These shifts made up the health professional’s model. Participants were able to identify key moments of change which had occurred during the programme, and it was possible to categorise the majority of these into the six shifts proposed in the health professional’s model.

The shift that occurred most frequently across participants was shift six where a sense of isolation and uniqueness, changes to feeling accepted, understood, and similar to others. Participants frequently cited the support they got from other group members, the relief at finding out that they were not the only one with their kind of difficulties and that they were suffering from a recognised condition, and a sense that the therapists understood their difficulties. Participants also noted that it was helpful to be able to share ideas with other group members, and to feel they could be of help to someone else.

The second most frequently coded shift was number three, where low self-esteem and feelings of helplessness and hopelessness change so that the individual develops higher self-esteem, and feels more in control and hopeful. Many participants reported particular strategies (e.g. activity management) that they found effective within the key moments coded under this shift.

Shift four describes the move from extreme to more balanced, thoughts, feelings and behaviour. Participants reported that they began to recognise that swinging from high activity levels to complete rest was unhelpful. Some of this learning occurred through the exercise component where participants reported they started by setting themselves exercise goals that were too high and learnt that a little exercise everyday is better than a lot one day and none the next. One participant noted that through observing the high standards of other group members he realised how this was not helpful in the long term. Another participant reported that they realised the importance of 'learning moderation in all things'. Participants reported that the planning and goal setting aspect of the programme also facilitated the achievement of a more balanced level of activity during the day.
The participants that reported key moments coded as shift one, frequently reported how the explanation given in the session seemed to make a lot of sense and that with the use of diaries they were able to see how the model related to them personally, which then confirmed their belief in its accuracy. Several participants also cited how the explanation helped them to understand the development of their illness and that their symptoms were related to the CFS/ME and not another medical problem as they feared.

There were 16 key moments which could not be categorised into one of the six shifts in the model. Closer inspection of the un-categorised key moments suggested that the first set of raters who identified key moments from the transcripts, may have identified key moments that did not actually represent key moments at all. In addition, where key moments were identified that could not be classified into the shifts in the model there was no clear theme indicating that there was another psychological shift not included in the model.

Limitations: The combination of qualitative and quantitative methods used in the present study takes advantage of the strengths of both types of methodology and enables in-depth investigation into complicated phenomenon such as the process of change. However there are a number of methodological limitations to the present study which will be discussed here. The participant interviews were retrospective and subject to memory biases. Future research could usefully explore participant perceptions of change at specific points during treatment. A methodology which relies on people’s capacity to articulate what they have learned, is subject to two possible limitations (Ridout, 2003, unpublished data). Firstly, it is likely that for some participants change may be happening at a level they cannot access, and while these participants may show improvements on outcome measures they are less able to articulate their thoughts or identify key moments. Conversely, there may be others who can articulate the ‘right’ answers without having actually ‘internalised’ the material or made a shift psychologically.

The coding method used in this study was intended to be a rigorous method of identifying shifts made by participants. However, the fact that agreement between raters did not reach significance may be due to a number of factors including different levels of experience between raters (qualified psychologists versus unqualified assistant psychologists), overlap between the different psychological shifts in the model, and the fact that key moments were removed from the context of their full transcript when they were coded into shifts.

The number of participants (n=17) is consistent with the prevailing trend among qualitative interview studies (i.e. n = 15 +/- 10, see 44). However, the limited statistically significant change found on outcome measures is probably due to both the power of the study and the timing of measurements. Other group studies of CFS/ME with larger samples, found statistically significant improvements in depression, anxiety, physical fitness, and physical performance (15, 43). Outcomes were measured immediately after the programme ended, whereas a number of
studies show that change may not be evident until at least 6 months after treatment has ended (45). It would be helpful to repeat the present study with a larger sample. In addition, demographic data such as ethnicity, marital status, and level of social support, was not collected therefore it is possible that the results of the study may not be able to be generalised to all CFS/ME populations.

The study lacked a control group, and it should be acknowledged that the improvements shown could have been due to non-specific factors rather than the specific intervention detailed here. A further possible limitation of this study is the use of the Oxford Criteria for diagnosis, instead of the more recent Canadian criteria (46), which are now becoming widely accepted as the most comprehensive clinical criteria available to date.

CONCLUSIONS

This study highlights the potential benefits of group work for people with CFS/ME including opportunities for validation from peers, as well as sharing and modelling, all of which are suggested to be important in the process of change. The findings also suggest the important role of health professionals in validating patient experience, facilitating the development of an adaptive conceptualisation, utilising strategies to encourage acceptance, and facilitating confidence through experimentation and modelling.

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