

A trial of client centred counselling over the telephone for persons with ME.

Author details:

Tony Ward, Kevin Hogan.

Contact details:

Dr Tony Ward, BSc PGDip MSc PhD CPsychol AFBPsS
Head of Psychology and Counselling,
Newman University College,
Bartley Green,
Birmingham,
B32 3NT.

Email: a.ward@newman.ac.uk

Dr Tony Ward's background is in health and neuropsychology, and he has more recently moved into the counselling sphere. He is head of Psychology and Counselling at Newman University College and works mainly with clients who have ME, MS or head injury. Kevin Hogan is a trainee counselling psychologist at Newman University College.

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A trial of client centred telephone counselling for persons with Myalgic Encephalopathy (ME).

Abstract.

The study described in this paper was designed to evaluate the potential of client centred telephone counselling for people with Myalgic Encephalopathy (ME). Fourteen participants were recruited via the main ME associations, and offered up to eight sessions of telephone counselling. The CORE measure was completed before and after, and change compared to scores collected during a waiting list phase. A paired t test showed that overall scores improved significantly, and the counselling was rated very highly in terms of usefulness. Whilst telephone counselling might seem somewhat limited compared to face to face methods, participant feedback suggested that it was very acceptable. The conclusion is that client centred methods delivered over the telephone can be a very effective form of intervention for clients with ME.

Keywords: client centred telephone counselling myalgic encephalopathy

Introduction.

Myalgic Encephalopathy (ME) / Chronic fatigue Syndrome (CFS) is characterised by fatigue, post exertion malaise, sleep dysfunction and pain. There are also typically neurological and / or cognitive symptoms such as difficulties with memory and concentration. Furthermore, some definitions also specify issues in at least one of either neuroendocrine, immunological or autonomic domains. For a diagnosis this pattern should have been ongoing for more than six months. (Carruthers et al, 2003).

ME is a complex condition which presents clients with many challenges. The onset of puzzling symptoms which are difficult to make sense of can cause considerable anxiety. Persistent symptoms of fatigue and cognitive processing deficits can be highly disruptive to clients lives, provoking changes in relationship and loss of role (Sterling, 2003, Ward et al, 2008). Furthermore, the contested nature of ME presents additional difficulties (Clark and James, 2003). Clients may have to face sceptical views from both relatives and health professionals, and indeed may have to examine their own past attitudes towards the condition. The notion that ME is predominantly “psychological” persists, despite good evidence for physical aetiology in at least a subset of cases (Komaroff, 2006).

Psychological interventions for ME have tended to be based on Cognitive Behaviour Therapy (CBT), and the notion that there may be “perpetuating factors” (Ridsdale et al, 2001). Such factors might include negative cognitions or unhelpful beliefs, e.g. about the effects of trying to increase levels of activity. There have been many trials of such approaches, e.g. Ridsdale et al (2001) and Wittowski (2004). Such interventions appear to yield some long term benefits (Deale et al, 2001). However, not all such trials have proved effective e.g. Bazelmans et al (2005). There is debate in the literature about what the aims of such interventions should be, i.e. to maximise the clients level of functioning vs. reduce fatigue to non clinical levels. If the latter is the case then such interventions are not particularly effective, e.g. Severens et al

(2004) achieved 27% remission in a group receiving CBT, compared to 20% in a control group.

Whilst some clients with ME describe their past experiences of CBT in very positive terms, some are highly critical (Ward et al, 2008). There is evidence for effectiveness of more generic counselling interventions (Thomas et al, 2006, Thomas and Smith, 2007). However, these studies are eclectic in terms of intervention design, leaving it unclear as to which specific components are effective. A large scale study (Ridsdale et al, 2001) appears to indicate that non directive, client centred therapy is as effective as CBT. The authors of this study describe the intervention in these terms:

"This model of counselling is non-directive and client-centred; it offers the patient an opportunity to talk through their concerns and difficulties in a non-judgmental and supportive environment."

However, in another part of their paper they describe the approach as "psychodynamic", making it unclear exactly what approach the counsellors were using, other than that it was originally intended to serve as a control for comparison with CBT.

Thus whilst there are some indications that interventions other than CBT can be helpful for ME, there is scope for further work on this issue. In addition it is clear that many people with ME suffer from restricted mobility (Thomas and Smith, 2007), and they often therefore access services remotely (Ward, 2008). It would be useful therefore to evaluate the efficacy of services provided at a distance. Whilst telephone counselling undoubtedly has limitations, there are indications that it can be an effective medium (Rosenfield, 1996, Sanders, 2007).

This study therefore set out to evaluate the provision of telephone counselling for clients with ME, using a client centred approach (Rogers, 1951, Gillon, 2007). Our rationale for this choice of model was that people with ME may

benefit from exploring some of the issues which affect them in an accepting and supportive environment, over an above the focus on “perpetuating factors” at the heart of many CBT studies. Of course this is not to say that a client centred approach would preclude any examination of “perpetuating factors”, only that this would be done at a point appropriate to the client and in their terms.

Methodology.

Participants

Fourteen participants were recruited via announcements in the newsletters of the ME Association and the Action for ME charity. The mean age was 48 (standard deviation 12, range 28-63), and there were ten females and four males. The data from a single fifty eight year old female participant was not included, since it emerged during sessions that there was a co-morbid medical issue which predominated.

Ethics.

This study was approved by the ethics committee of the higher education institution in which it was based. All participants signed a consent form, after being briefed about the study via telephone and receiving a written information pack. On receipt of the signed consent form they were entered into the study.

Procedure

Once accepted into the study, clients completed the CORE outcomes forms (Evans et al, 2000 and 2002). They were then placed on a waiting list. After eight weeks on the waiting list, clients were asked to complete a second

CORE form. This then provides a baseline of change across eight weeks of time spent on the waiting list.

After completion of the second CORE form, clients were slotted into the next available intervention. A third CORE form was completed at the start of the intervention phase. Clients were offered up to eight sessions of telephone counselling, with the option of extending this if it was felt appropriate, e.g. if there were concerns for the clients welfare at that point. All clients were offered the possibility of referral to local services. At the end of the intervention, clients completed a final fourth CORE form.

All of the counselling sessions were offered by the first author, who is trained in the client centred approach. Sessions were recorded so that themes could later be identified. The work was supervised by a chartered counselling psychologist.

Approximately two weeks after the end of the final counselling sessions, the clients were contacted by the second author and interviewed about their experiences. During this interview the clients were asked to rate the counsellor in terms of their understanding of the clients issues (empathy), being genuine as a person (congruence) and valuing them as a person (unconditional positive regard). Each of these was rated out of ten, with zero being low and ten being high. They were also asked to rate how useful they felt the sessions had been, again out of ten.

During the interviews, clients were invited to discuss their experience of telephone counselling as opposed to face to face counselling.

Results.

Table 1 shows the mean process ratings given by clients after the end of the intervention. As can be seen from the table, clients rated the counsellor highly on the three dimensions. The intervention was rated reasonably highly on average, though the score reflects the fact that some of the clients did not rate the intervention highly. Two clients rated usefulness as one and three respectively, all other clients ratings were six or above.

Table 1 about here.

Table 2 shows the changes observed in the CORE measure in terms of the three subscales and the total score. The change across the intervention in the three CORE dimensions of wellbeing, problems and functioning was negative. This suggests that scores were improving. To see if the change during intervention was significantly different from that during the waiting list phase, paired t tests were carried out on the change scores, using a one tailed test. The degree of change was significantly different to that observed during the waiting list period for these three variables. In contrast, the change in risk score across the intervention was positive, suggesting a deterioration, though there was no significant difference compared to the waiting list phase. The apparent deterioration in risk scores is due to three clients.. All other clients either stayed the same or improved. For the three clients whose

scores deteriorated, the changes were from zero to fourteen, one to seven and three to eight respectively. These clients will be considered further in the discussion.

Table 2 about here.

Themes covered during sessions.

Session transcripts were reviewed to identify the nature of client issues discussed. These included:

- Loss resulting from ME, e.g. of jobs, status, relationships.
- Difficulty in relating to others due to the misunderstandings of and attitudes about ME.
- Anger due to the way in which relatives had reacted to the client developing ME.
- Loneliness and isolation due to the physical and mental constraints of ME.
- Regret at not having made more of life prior to the onset of ME.
- Trying to adjust to the constraints of living with ME.
- Concern at whether one could be doing more to overcome ME.

Of these the two themes which recur most frequently were dealing with the attitudes and misunderstandings of others, and the difficulty of making an adequate adjustment. In particular, clients are acutely aware of the need to

pace themselves, but find this difficult because of the delay in reaction to exertion.

Reactions to telephone counselling.

There were both positive and negative reactions to telephone counselling. On the positive side some clients recognised that it enabled them to access counselling because they were housebound. One client commented that it was pleasant being able to lie on the sofa and talk to someone, and use their imagination to think about what the other party might look like. One client felt it was helpful as she felt very self conscious.

Negative comments were mainly about the disadvantage of lack of face to face contact, not being able to see what the other person is doing and not being able to access non verbal communication.

On balance therefore, whilst many clients felt there is something lacking in telephone work, there is a recognition that it offers a practical alternative where people are not able to get out and about, and where there is no local counselling provision.

Discussion.

This study has reported a small trial of client centred telephone counselling for participants with ME. The clients rated the counsellor highly on dimensions of understanding, being genuine and valuing. There were significant

improvements on three of the four dimensions measured by the CORE outcomes scale, and in the overall scores. The intervention was on the whole given high ratings for usefulness.

Although this study has produced favourable outcomes on most of the dimensions measured by the CORE outcomes scale, it should be noted that this appears to be in part due to the fact that scores tended to increase slightly during the waiting list comparison phase of the study. Having said that, there were clear improvements across the intervention phase.

The risk dimension of the CORE measure was the exception to the pattern described above. This showed a slight deterioration in scores, though this was not significant. This decline was due to three clients, one of whom showed a marked change from zero to fourteen. This client had suffered considerable work related trauma due to trying to work for a number of years with the condition in the face of unsupportive management. During the sessions they were able to recognise the feelings they had been suppressing. The client was provided with additional sessions and subsequently they sought a referral from their GP and when followed up they were working with a trauma specialist. Thus the intervention allowed this client to recognise the impact of the condition and seek appropriate further referral. Of the other two clients whose risk scores increased, one had developed a physical complaint during the intervention which was affecting her mood, whilst the other had ongoing depression which she was being referred to a specialist for. To our knowledge one additional client accessed further counselling after the study.

In their feedback this client stated that she felt the intervention had been very useful in prompting her to explore some of her personal issues and that she had purposely sought out a client centred counsellor for this.

The above discussion highlights that a short eight session contract is insufficient for some clients in this population. This was recognised as a potential issue at the outset. We were very careful to inform the participants that this study was evaluating the use of a short contract. The possibility of additional sessions was held out, in case clients were in a difficult place in their process to terminate in session eight. It would be interesting to see in further work whether other types of client might come forward if a longer contract was offered.

During the sessions, clients discussed a range of issues. Coming to terms with the condition, adjusting to its constraints and accepting the losses it imposed were common themes. The effects on relationships both within and outside the family were also explored by the majority of clients.

The intervention was scored highly for usefulness by most clients, with a minimum of six and many eight and nines. There were however two exceptions to this who gave scores of one and three respectively. Both of these clients seemed to be trying out the intervention to see if it could make a real difference to their physical condition and symptoms. Such expectations seem to be around in the ME community due to the focus of many CBT services on restoring function. In the current authors opinion, this may be an

unrealistic expectation for many clients with severe enduring ME, and therapists should be careful to explore client expectations at the outset of any intervention.

Following on from the above point, it may be important to consider the characteristics of the sample in this study. All participants were drawn from established ME charities. It may be that people who join and attend support groups represent a particular portion of the population of people with ME. In particular they may be people with more severe versions of the condition and experiencing enduring symptoms. All of the participants in this study had experienced serious impacts on their lives and work due to their condition. Most had experienced break up of relationships, and virtually all had been unable to continue work. Thus it is difficult to say how useful this intervention might have been with less severely affected clients.

Another possible factor in recruiting people from support groups is that they may have been influenced by the support groups agenda. The ME support groups tend to lobby for services, and tend to take the view that ME is poorly supported and services offered are not always seen as appropriate. Thus the participants in the study may have seen taking part as a way of trying to ensure more resources are made available to the ME community. If so, they may have been more inclined to give positive results. Thus further work could usefully be carried out with clients recruited from other sources.

In terms of the telephone intervention itself, this was felt to have limitations, but offered a practical way of accessing a service. The counsellor was aware of having to rely much more on the non verbal cues offered through vocal intonation. Given that clients were in their own homes, interruptions to sessions were sometimes experienced, but this was not felt to be overly detrimental.

In conclusion, a client centred telephone based intervention does appear to have something to offer clients with ME. It allows clients to explore their experiences and challenges of ME in a supportive relationship, following their own direction. This allows clients to set their own agenda, and gives them a wide scope. In contrast, clients with ME can find other approaches limited and narrow in focus (Ward et al, 2008). Of course we would expect counselling psychologists using a client centred approach to be able to bring a wide variety of theoretical and psychological insights to bear on developing their empathy (Gillon, 2007), the exploration of which could provide additional fruitful avenues for research investigation.

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Table 1. Process ratings.

	Mean	SD
Counsellor understanding	8.5	1.2
Valuing	9.0	0.8
Genuineness	9.2	0.6
Usefulness	6.6	2.3

Table 2. Means (and sds) of CORE subscales, showing change and significance.

Measure	Waiting list			Intervention			Significance
	Before	After	Change	Before	After	Change	
CORE wellbeing	6.6 (2.6)	7.5 (3.4)	0.9 (1.9)	7.9 (3.6)	5.8 (3.2)	-2.2 (3.8)	t= 2.1, p<0.05
CORE problems	22.0 (8.4)	23.6 (8.8)	1.6 (3.4)	24.0 (8.7)	19.5 (7.6)	-4.5 (9.3)	t= 1.9, p<0.05
CORE functioning	17.5 (5.8)	18.8 (6.2)	1.4 (2.6)	19.1 (6.5)	15.6 (8.1)	-3.5 (6.3)	t= 2.2, p<0.05
CORE risk	1.8 (1.2)	2.4 (2.2)	0.6 (1.6)	1.5 (1.8)	2.7 (4.4)	1.2 (4.6)	t= 0.5, p>0.05
CORE total score	47.9 (13.5)	52.5 (15.8)	4.5 (5.8)	52.5 (16.2)	43.6 (21.4)	-8.8 (22.0)	t=2.0, P<0.05