

The Experiences of Counselling for Persons with ME

Tony Ward, Kevin Hogan, Viki Stuart, Elizabeth Singleton

Newman University College, Bartley Green, Birmingham, B32 3NT

a.ward@newman.ac.uk

Abstract

A number of studies have evaluated counselling interventions for people with Myalgic Encephalitis, but few report client perceptions in any detail. This study seeks to explore client perceptions using a qualitative methodology. Twenty five participants were interviewed about their experiences in counselling, as people living with Myalgic Encephalitis. The interviews were transcribed and subject to a thematic analysis using grounded theory principles. The analysis showed that people with Myalgic Encephalitis endure significant changes to their lives, often involving great loss and trauma. In seeking help through counselling, participants had experienced a wide variety of approaches and there were positive and negative perceptions of each. Other perceptions involved the characteristics of the therapist and the way in which interventions were carried out. Recommendations for practitioners are given.

Keywords: Myalgic encephalitis; chronic fatigue syndrome; counselling; user perceptions

Introduction

Myalgic Encephalomyelitis (ME) / Chronic fatigue Syndrome (CFS) is characterised by fatigue, post exceptional 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 and disputed condition and this feature itself complicates the picture for people living with ME (Clarke and Jones, 2003; Sterling, 2003). Taylor (2005) points out that ME is not like many other disabilities in that it is not readily observed, and its effects are variable. Previous pilot work carried out by some of the current authors suggested that people with ME tend to subscribe to a range of beliefs about their condition, in particular its physical causation and long term resolution. People with ME also report a range of psychosocial difficulties, particularly with their relationships (Bentall et al, 2002; Deale et al, 1998; Sterling, 2003).

Given the difficulties experienced, it is not surprising that many people with ME seek support through counselling (Albrecht and Wallace, 1998; Chalder et al, 2000). Frequently clients with ME will be offered cognitive behavioural therapy (CBT), given its prevalence within the health sector. There are many studies which report positive outcomes with CBT, such as Wittowski et al (2004) and Deale et al, (2001), whilst others are less positive, such as Bazelmans et al (2005). It is suggested that CBT for people with ME who are psychologically minded, i.e. who are willing to subscribe to the view that their problems may at least partially be located in the mental as opposed to physical sphere, are likely to do better. Those subscribing to a physical explanation of their problem may do less well (Bentall et al, 2002). In contrast, Deale et al (1998) suggest that it is a willingness to combat avoidance behaviours that predicts outcome rather than any particular belief about causation.

Bleijenberg et al (2003) suggest that the main goal of CBT for such clients is to help them find an optimal level of activity. They suggest that for many clients this may mean substantial cuts in activity levels, as trying to do too much in the face of the

condition can be counter productive. This assertion is supported by Van Hoodenhove (2006). This appears to contrast with the stated aims of other studies, where efforts seem to be directed towards reducing symptoms and increasing activity levels, with outcome often being assessed in terms of full recovery (Knoop et al, 2007; Severens et al, 2004).

Knoop et al (2007) found that while two thirds of their treatment group showed some improvement, only twenty three percent could be said to be fully recovered. Severens et al (2004) found that six months after treatment, twenty seven percent of clients receiving CBT had improved, but the figure for the control group was twenty percent. The latter seems to suggest that the spontaneous remission rates observed in ME are often close to the figures seen in active treatment conditions. Deale et al (2001) conclude that CBT should not be seen as a cure for ME/CFS. Some recent studies have been encouraging in terms of what can be achieved through CBT and other counselling interventions (Thomas, Sadlier and Smith, 2006; Thomas and Smith, 2007), but as with previous work these studies fail to examine the long term significance and ultimate benefit to clients. Thus, the literature on counselling for people with ME remains unclear. Furthermore, whilst there is discussion in the literature of CBT, there is little evaluation of the use of other approaches with the condition.

The current study is an initial attempt to explore users' views and perceptions of their experiences of counselling. Given the lack of clarity evident in the literature about the nature of ME and the efficacy of treatment options, we expected to find a diverse range of views. We were very keen to find out from users, in their own words, what they found useful and what they found unhelpful or negative in their experience of counselling. Participants were also invited to describe the kinds of issues which they discussed in counselling. The subsequent transcripts provided a wealth of information about the condition and its effects. It is clear that this material is highly pertinent to the kinds of issues which counsellors can expect clients to bring. Table one provides an overview of the participants' accounts of the onset and development of ME.

<insert table one about here>

Methodology

A qualitative methodology was chosen to generate rich interview data. Unstructured interviews were used which were then analysed using thematic analysis following grounded theory principles (McLeod, 2003, Strauss and Corbin, 1990). We are not aware of any previous systematic attempt to collect the views of past counselling clients with ME.

Participants

Twenty five people with ME were interviewed, recruited through advertisements in the newsletters of the ME Association and the Action for ME user group. The adverts asked for volunteers who had experienced any type of counselling and who were willing to share those experiences in a telephone interview. Participants who believed they had received a counselling intervention delivered by a counsellor, therapist or clinical psychologist were admitted to the study. The mean age of participants was 44, standard deviation 11, with a range of 23 to 65. All participants had received a formal diagnosis of ME from a medical practitioner. There were four males and twenty one females. Length of illness ranged from two to nineteen years. Length of counselling varied from eight weeks to one year, and included both NHS and private settings. Given that some time had elapsed since counselling, we were not able to systematically evaluate the training and background of the counsellors who had delivered the therapy.

Ethics

Ethics approval for this study was obtained from the Newman University College Ethics Committee. Written and verbal consent was obtained from all participants.

The Researchers

Tony Ward is a counsellor and health psychologist with an interest in ME. Kevin Hogan is a trainee counselling psychologist, whilst Viki Stuart and Elizabeth Singleton were psychology undergraduates at the time of the study. The motivation was to explore client experiences of a wide range of counselling modalities, with the expectation that a range of both positive and negative experiences would be described.

Procedure

Participants were telephoned and the nature of the study discussed. A date was arranged when they could be interviewed and they were then phoned back at the agreed time. During this second call, participants were reminded that calls were being recorded for transcription, and they were asked to verbally confirm that they were happy to take part in the study. Participants were offered the opportunity to be interviewed over a number of sessions if this was helpful due to difficulties with fatigue or concentration, but this proved not to be necessary.

The interview began using the general phrase “As you know we are interested in the experiences of people with ME, and the experiences they have had of different types of counselling, and we would be interested in anything you would be willing to share with us”. The interview direction was determined by the interviewee, with the interviewer prompting and encouraging but being careful not to direct. The exception to this was that specific prompting about the nature of interventions used in the counselling was offered if the participant had not spontaneously volunteered this. The rationale for occasional prompting was that we wanted to be able to get a feel for the type of intervention the counsellor was using. Thus, participants might be prompted by, “you have not really said anything as yet about the kinds of things that happened in the counselling, I wonder if you could tell me more about that?”.

Interviews varied in length from twenty to ninety minutes. They were digitally recorded and the sound files were then transcribed for content. The twenty five transcripts were analysed using thematic analysis by the authors and the resulting thematic structures were compared and discussed until a final agreed thematic structure was derived. The thematic structures were remarkably consistent between the authors and relatively little adjustment was required to arrive at the final agreed version. Themes were loosely defined as “single coherent units of meaning” within the text, which were then subject to classification and categorisation.

Results

The twenty five participants interviewed appear to have experienced a variety of counselling approaches and interventions. It is difficult to be precise about who had received which approach to counselling, since many participants were unclear about the theoretical orientation of the counsellor they had seen. From the material, it seems

that participants had experienced CBT, person centred, psychodynamic and integrative/eclectic approaches. Eight participants were clear that they had received CBT, and a further four described CBT techniques in some detail. This seems to be the predominant single approach experienced by the participants.

In this section we will present the main themes and outline the sub-themes, giving examples of participant statements as illustrations where this is helpful. The thematic structure can be found in table two. Participant statements are given in italics.

<Insert table two about here>

Experiences in counselling of people with ME

Interventions

In broad terms participants described four types of interventions aimed at managing their activity, stress or thoughts, or to examine the influence of the past on their current situation. Activity management included devising routines, increasing the level of activities, keeping diaries, setting goals and pacing. Of these, the most useful was pacing (in fact this seemed to be the most valued aspect of all counselling interventions). By this, participants meant becoming sensitive to their energy levels and monitoring how these were affected by activity. They were invited to regulate activity levels to maximise energy without risking relapse. Participants described how in the early stages they often got this wrong, resulting in periods of crushing fatigue and pain. Learning this relationship between activity and energy levels was complicated by the fact that there was often a delay of sometimes several days before the full impact was felt. For these participants, exercise regimes and sometimes activity programmes were viewed very negatively. The suggestion was that the participants were often pushed to overdo it, leading to significant relapse.

“...they told me to exercise and I went swimming and of course it got ten times worse and I ended up in bed.”

“...we used a very strict pacing programme, which I think is the main thing I need to do.”

Relaxation and meditation techniques were invariably seen positively with participants talking of reduced stress levels in the impact of their condition and their life activities.

“I learnt some new relaxation techniques, which was useful though they didn’t help the ME at all.”

Participants’ responses to thought management strategies, e.g. looking at some thoughts as negative in content and therefore counter productive, were mixed. Some participants found these kinds of suggestions very patronising and negative. For example, it was felt by some that their ongoing condition was being blamed on their negative outlook. One participant found this very difficult as they felt they had always been very positive in fighting for improvement. Others found such notions simplistic. Other participants however found such interventions very useful, for example helping them to counter very unrealistic or catastrophising reactions.

“I was insulted by the idea that we would do anything to impair our recovery – we fight for it.”

“...the counsellor said “oh, you must be having negative thoughts”, talking to me like I was a naughty child.”

“...she gave me some sort of chart, ABC, actions, behaviour, consequences, and it was like someone had turned a light on for me.”

There were very few participants in this sample who described being encouraged by their counsellor to look at their past experiences. Two participants described this intervention and felt very negatively about it. This seemed to be because they thought the suggestion was that the cause of their ME might be rooted in the past, whereas they firmly perceived their difficulties to be rooted in the here and now. They firmly rejected a suggestion of a psychological cause for their condition.

“...he wanted to delve into my past, he wanted me to think about bad things in my life...I thought no, I don’t want to go down this route.”

Reflections on the nature of the relationship with the counsellor

Negative reactions to counsellors tended to involve poor communication and not understanding the condition together with non empathic responding. Participants gave some very powerful examples of these.

“...and she [the counsellor] said “not accepting our illness today are we?””

“I was really cross after three sessions, she didn’t have a very good understanding of my illness, I gave her a book!”

“...there is a danger with some counsellors who don’t understand ME to focus on the depression”

Positive reflections on the other hand involved the counsellor listening, understanding and offering appropriate challenge. For example,

“...it was good to have someone to talk to that was non judgemental and gave the odd bit of advice.”

“...when the counsellor is truly empathic with you, it’s at that moment when there’s a release.”

“...it’s a very definite release, almost a click, it’s like I don’t need to hold on to these unhelpful thoughts and feelings.”

Reactions to counselling

Participants’ reactions to the counselling were classified as either positive or negative. In terms of negative reactions, one issue mentioned by several participants related to the physical impact of the counselling for someone with severe ME. For example, they described the difficulty of making their way to and from the session each week, and the strain of keeping up a session of fifty minutes.

The majority of negative reactions related to perceptions of the counsellor and the counselling process. People with ME can find certain suggestions about their condition very challenging; in particular that it might not be physical, that they have control over it, or that its roots lie in the past. Certain styles of counselling were perceived as controlling, patronising and a form of brainwashing. These perceptions generally related to what the participants understood as CBT. Counsellors who did not seem to have an understanding of ME were perceived negatively. Positive reactions involved feeling listened to by an empathic counsellor who understood the condition.

Perceived benefits of counselling

The perceived benefits of counselling were generally in line with what one might expect a counselling relationship to offer; in other words, a good relationship with someone who understands and is outside of the immediate situation. Having this weekly stimulus was perceived as beneficial. Coping with stress, having realistic goals and learning to pace were more practical benefits.

“I don’t think it really makes any difference to the ME, it can only make you feel better about yourself.”

“It helped me to deal with all the emotional stuff that was coming up.”

Other Findings and Limitations

What was evident from the interviews was that participants were strongly disposed to see their condition as physical in origin. They reacted negatively and with suspicion to any suggestion that their condition might be psychological or prolonged / exacerbated by psychological factors. This outcome can be supported by existing research (Bentall et al, 2002).

It is important to note that none of the participants in this study described themselves as fully recovered. They were all still grappling to some degree with the issues presented by ME, though most were considerably better than during their initial acute phase. Given that in the Severens et al (2002) study, twenty seven percent of their

sample receiving CBT had experienced full recovery, it is noteworthy that none of our participants were in this category. However, given that two thirds of participants in CBT trials are typically reported as improved, many of our participants would have rated themselves as falling into this category.

It is possible that the lack of fully recovered participants in our sample reflect the recruitment strategy. All of the participants were recruited via the ME Association and the Action for ME user group. As a consequence it is possible that most participants would have had a long history with unremitting symptoms. Those referred for counselling in the earlier stages of their condition and who subsequently experience a favourable outcome may not join or remain as members of such support groups. We note that the findings in this study relate mainly to those people who do not experience a full recovery, which some studies suggest may be two thirds of cases (Knoop et al, 2007). We must also caution about the points relating to psychodynamic approaches, where there were only two participants that clearly described having experienced this type of counselling.

It is interesting to note that many of the experiences of counselling as described by the participants are reminiscent of the experiences of clients in general (Hynan, 1990; Manthei, 2007), but with some extra considerations due to the nature of the condition itself. Further research could look at particular client experiences in more depth. It might also be interesting to look at subgroups of clients, e.g. examining severity, age of onset, gender etc.

Discussion and implications for practice

This study raises some important implications for practice which will be discussed. First, counsellors working with clients who have ME need to be thoroughly familiar with ME and its effects. Counsellors who have experienced ME themselves may be advantaged in this, but experience of similar conditions such as post viral syndrome may also be helpful. At the very least counsellors should try to read first hand accounts of the condition.

Second, counsellors should be very careful to avoid giving negative messages to clients, or using statements which clients might find devaluing. Most people with ME

are committed to the concept that ME has a physical causation, and they are very wary of any suggested role for psychological factors. Counsellors need to work carefully to ensure the client sees interventions as a way of helping them cope with the condition, rather than a way of correcting fundamental aetiological factors. Similarly, counsellors should avoid any suggestion that clients may somehow be prolonging their condition. In our view, it would be helpful for counsellors to be aware of some of the literature on physical causation of ME, such as the work of Komaroff, (2006), to counter some of the alternative theories that exist in our culture.

The counselling experiences of people with ME as described in this paper point to a need for counsellors to be able to offer a range of interventions, including CBT and person centred (and from our own experience with clients, psychodynamic perspectives can be useful too). Ideally this integration should be client driven, i.e. the counsellor will offer interventions based on client need and in consultation with clients. All counsellors should be familiar with the concept of pacing and how to help clients work on this coping technique.

Given that the majority of clients are unlikely to fully recover, counsellors should be willing to address client expectations in a realistic way. In this study, none of the participants felt that they had achieved a full recovery and a number expressed the view that they were concerned that approaches were often presented as a possible cure. As Song and Jason (2005) point out, those clients that do recover may not have “pure” ME, and may therefore be improving because the CBT addresses some other underlying issue. The notion that counselling can somehow “cure” ME seems therefore somewhat unrealistic (Deale et al, 2001). However, we feel that counsellors would be very justified in saying to clients that counselling may positively impact on issues arising from ME such as grief, loss, anxiety and depression.

Conclusion

This study has reported the experiences of people with ME following counselling. Participants experienced a wide variety of approaches and there were positive and negative perceptions of each. We conclude that counsellors should strive to understand the condition, to present messages to clients which are perceived positively, and to be realistic in addressing client’s expectations.

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Table 1
Participants' Experience of Counselling – Thematic Structures

Types of Interventions

1. Activity related
 - i. Routines
 - ii. Diaries
 - iii. Pacing
 - iv. Increasing amounts
 - v. Setting goals
2. Stress management
 - i. Relaxation training
 - ii. Meditation
3. Thought management
 - i. Examining negative thoughts
 - ii. Considering how thoughts influence feelings
 - iii. Mindfulness
4. Examining the influence of the past
 - i. Looking at life history
 - ii. Looking at the influence of early relationships

Reflections on the nature of the relationship with counsellor

5. Negative reflections
 - i. Poor communication
 - ii. Not understanding nature of ME
 - iii. Non empathic responding
6. Positive reflections
 - i. Counsellor listens
 - ii. Counsellor understands
 - iii. Counsellor offers appropriate challenge

Reactions to counselling

7. Negative reactions
 - i. Difficult to get to counselling, results in tiredness
 - ii. Controlling
 - iii. A type of brainwashing
 - iv. Patronising
 - v. Suggestion that lack of recovery is under control
 - vi. Suggestion that ME is not physical
 - vii. Resistance to certain suggestions, e.g. looking at past
 - viii. Lack of counsellor interaction
8. Positive reactions
 - i. Counsellor's empathy was facilitative
 - ii. Has led to more realistic views
 - iii. Felt listened to
 - iv. Counsellor conveyed knowledge and understanding of ME
 - v. Beneficial in the early stages of ME

Perceived benefits of counselling

9. Helps to deal with stress
10. End up with more realistic outlook and goals
11. Helps with pacing
12. There's someone to talk to each week
13. It gets you out each week
14. It provides an outlet outside of the family
15. It is with someone that understands
16. One can establish a good relationship

Table 2
The Impact of ME

1. Onset

- a. Virus, flu
- b. Glandular fever
- c. Middle ear infection, labyrinthitis
- d. Stress, life trauma

2. Symptoms

- a. Lack of energy, fatigue
- b. Difficulty thinking, slowing of thoughts
- c. Physical pain, inability to move
- d. Word finding difficulties
- e. Depression, anxiety attacks
- f. Slow decline in functioning

3. Anxieties about possible diagnosis

- a. Multiple Sclerosis
- b. Alzheimer's Disease
- c. Brain tumour

4. Effects on day to day activities

- a. Severe fatigue limits activities
- b. Can't work, early retirement
- c. Can't drive, or only short distances
- d. Marriage / relationship break up
- e. Loss of relationships e.g. in family
- f. Homelessness
- g. Inability to do basic activities, housework etc
- h. Inability to do basic self care and hygiene
- i. Periods of being bedridden

5. Other peoples' attitudes towards ME

- a. Is ME a genuine condition?
- b. ME accounts for all health complaints (from GPs)
- c. ME is caused by stress
- d. Not understood, people only see you when well
- e. Linked to mental illness, stigma

6. Personal reactions to being diagnosed with ME

- a. Time taken to get diagnosis is very long
- b. Relief at finally knowing what it is
- c. Frustration, knowing that ME is misunderstood
- d. Denial, I cant have anything serious
- e. Treatment offered is unsuitable
- f. Not much help available
- g. Need to rely on self help
- h. Depression
- i. Difficulty accepting changes in lifestyle
- j. Negative effects of medication offered i.e. anti-depressants, "zombie pills"