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25% M.E.GROUP

M.E. Generic Members Survey Questionnaire Results

The questionnaire was completed by M.E. Sufferers who are or have been Housebound / Bedbound for 2+ years

Questionnaire was distributed in October 2001, analysis completed in March 2002

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A copy of the original Questionnaire results and Report can be obtained by sending a donation of £2.50 (black & white) or £5.00 (colour) to cover reproduction and postage and package costs from the above address and is subject to the above reserved rights.

Contents

APPENDIX

1.0 Post Codes for each Region (Q22-24)

2.0 Copy of Original Questionnaire Issues

Acknowledgements

The design, presentation and publication of questionnaire survey's is a popular recognised strategic scientific method, extensively used to analyse and produce data in a structured and coherent way, which is understandable to all readers.

The notion of 'simplicity' in presenting and recording data collated was welcomed in survey one and two compiled for and on behalf of the 25% M.E. Group in July 2000 and August 2001. For this reason similar formats shall be replicated herein.

Special thanks go to Margaret Totten, BSc (Hons), who gave so much of her time and energy, first in compiling the information required for the questionnaire, and later for collating the data obtained and using her computer skills in analysing and presenting the results simply and clearly.

Thanks also go to Tricia Smith, Doris Jones, MSc., Pat Williams and many others who helped with 'many' revisions of the questionnaire design and structure. A special 'thank you' goes to all those who completed the questionnaire - thank you all for your input.

The 25% M.E. Group hope that the results from this questionnaire survey and those compiled in year 2000 & 2001 will collectively in some way help push forward the important of much needed research into the needs of severely affected M.E. sufferers.

Simon Lawrence
25% M.E. Group Co-ordinator

Questionnaire Results

INTRODUCTION

M.E. (Myalgic Encephalomyelitis) represents a real problem today not only at a clinical level but also at a socio-economic level. The burden and disability may be greater than that caused by diabetes, epilepsy, multiple sclerosis. The volume of published research reflecting sufferers multi-symptoms, aetiology, treatment types and number of sufferers all of which are acknowledged and included in the report on M.E. from the Royal College of Physicians, Psychiatrists and General Practitioners which acknowledge the high percentage of the population suffering from this illness M.E. is still under-diagnosed and under-treated.

Such a situation places an extremely heavy burden not only on the individual but also on the family and community. It is evident that major factors resulting in the picture described above include prejudice and misinformation surrounding this topic, not only among the sufferers and their families, but also in the general population. Improved information and education appear to be both valuable and necessary tools to fight the present situation.

In many instances, when discussing the impact of this illness on the individuals, the families and on the community, the voice and the feelings of the sufferers are ignored and interventions planned without consultation or any form of participation by the 'users' or the sufferers who are the object of such planning.

In responding to the above the 25% M.E. Group distributed a Generic Postal Questionnaire (October 2001) in an attempt to collect patient focus data for presentation to various Health Care Professionals and Agencies which may be used to assist in the planning stage for every health authority. The Generic Questionnaire was compiled from the findings of 2 previous survey's undertaken by the Group (July 2000 : August 2001).

This report contains a preliminary analysis of the responses received from 162 severely affected M.E. sufferers, all members or supporters of the 25% M.E. Group who were/had been Housebound/Bedbound for 2+ years. The survey is not a clinical trial, bit an independent survey which may be viewed as providing patient views, experiences and ideology to assist health care planners and assessors who undertake plan and arrange services based upon a patients 'needs assessment'. It is hoped the data collated will help focus the views and actions of many statutory bodies that M.E. sufferers can, should and do deserve the same rights to diagnosis, treatment and respect as all other patient groups.

The data collated describes the global analysis of all responses received : it does not describe the situation in each county, region, town or country.

METHOD : DATA HANDLING & STATISTICAL ANALYSIS

A postal questionnaire was issued to a total of 250 members and supporters of the 25% M.E. Group who were/had been Housebound/Bedbound for 2+ years The handling of the questionnaires was a simple count of the questionnaires received. Data collated was a single data entry resulting in an Access data base. No controls were made on the data, except for facilitating analysis. The data were analysed without weight. The analysis was carried out on the complete data set, ie all available questionnaires including the 6 respondents who reported a diagnosis of PVFS.

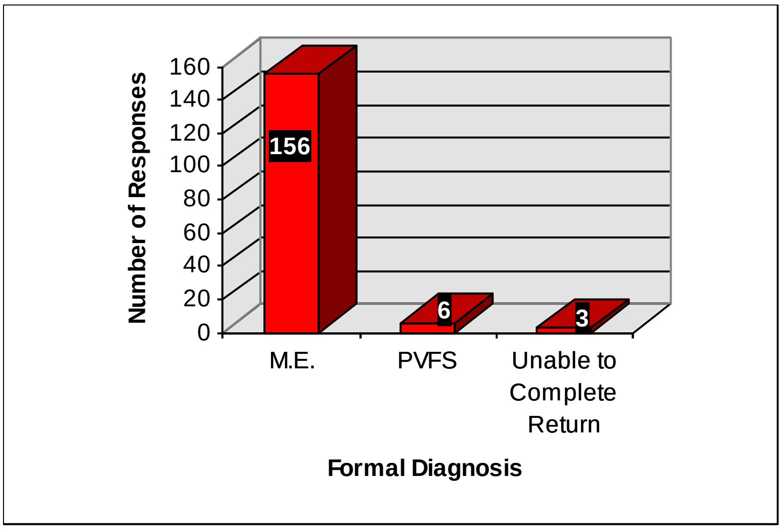
RESULTS

Size of Sample

A total of 165 sufferers responded to the questionnaire. However, analysis was conducted on 162 respondents because 3 reported they were to ill and unable to complete the questionnaire.

Information about the Illness

Question 1a - Have you been formally diagnosed as suffering from ME./CFS?

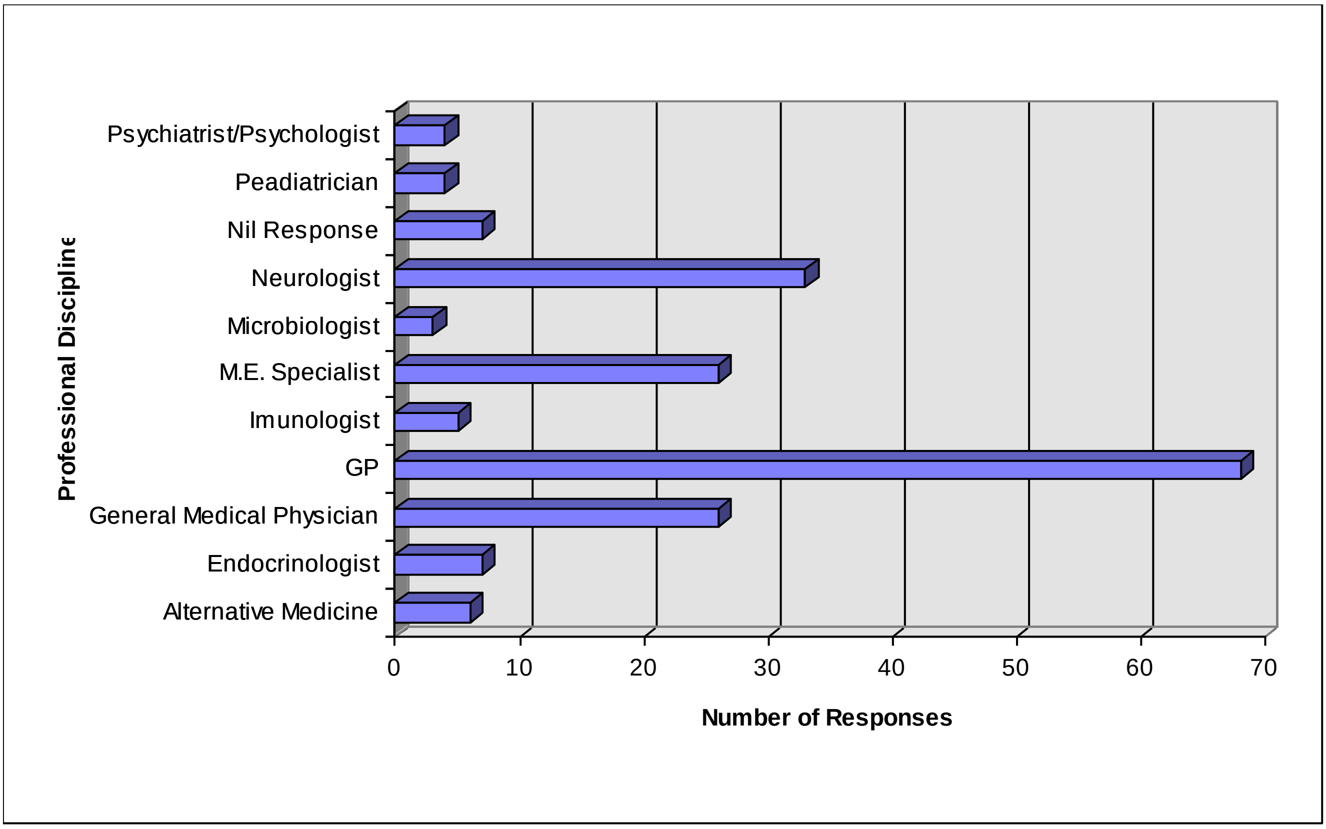


Diagnosis	Total Number
M.E.	156
PVFS	6
Unable to Complete Return	3
Total	165

COMMENTS:

- 3 respondents returned the questionnaire as they were to ill / unable to complete the questionnaire
- The information as presented is fairly straightforward to interpret therefore no other explanation was thought necessary.

Question 1b - Who gave you the diagnosis of M.E./CFS?



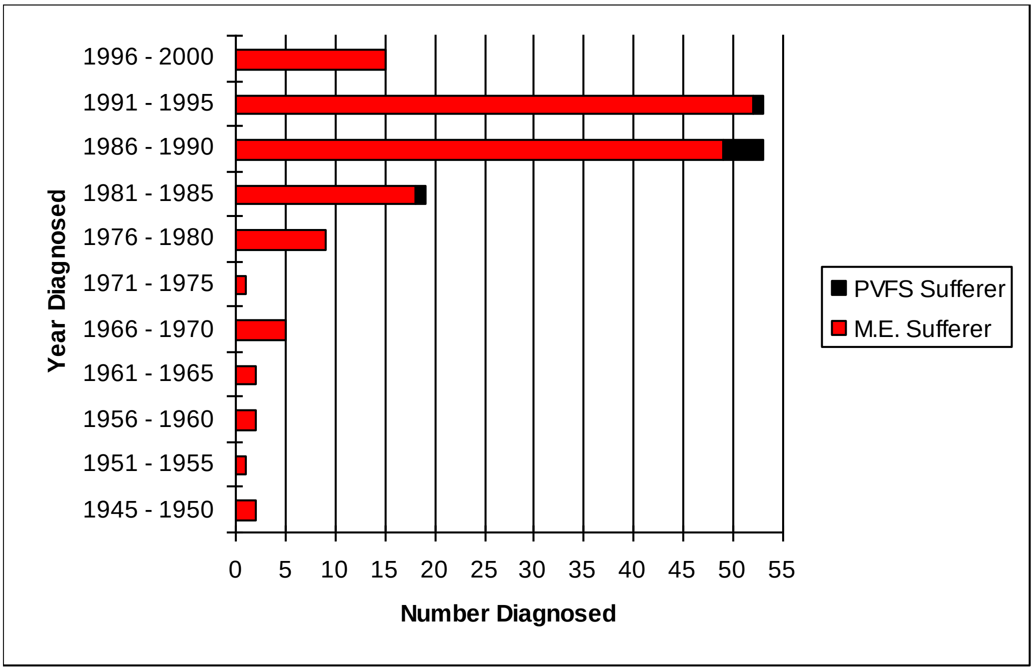
Professional Discipline	M.E. Diagnosis
Alternative Medicine	6
Endocrinologist	7
General Medical Physician	26
GP	68
Immunologist	5
M.E. Specialist	26
Microbiologist	3
Neurologist	33
Nil Response	7
Paediatrician	4
Psychiatrist/Psychologist	4
Rheumatologist	1
Total	**190**

- The majority of the respondents recorded multiple responses.

- In the main the majority of cases were diagnosed by a GP (35.7%) or by (in some cases confirmed by) a neurologist (17.3%) and in a smaller percentage by the Psychiatrist / Psychologist or Paediatrician (2.1%).

- The information as presented is fairly straightforward to interpret therefore no other explanation was thought necessary.

Question 2 - When did your illness start?

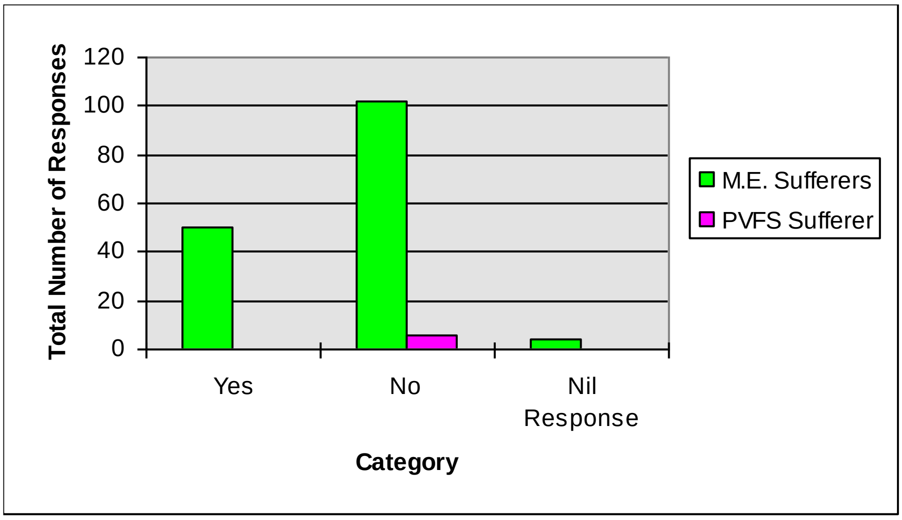


Year	M.E. Sufferer	PVFS Sufferer
1945 - 1950	2	0
1951 - 1955	1	0
1956 - 1960	2	0
1961 - 1965	2	0
1966 - 1970	5	0
1971 - 1975	1	0
1976 - 1980	9	0
1981 - 1985	18	1
1986 - 1990	49	4
1991 - 1995	52	1
1996 - 2000	15	0
2001 - Present	0	0
TOTAL	**156**	**6**

COMMENTS

- Period 1986 - 1995 (33% = 33%) is significantly higher than any other period.
- Caution in considering these findings must be taken as respondents were reporting on perceived start date for illness onset rather than formal diagnosis.

Question 3 - Have family members, colleagues or contacts also been affected?

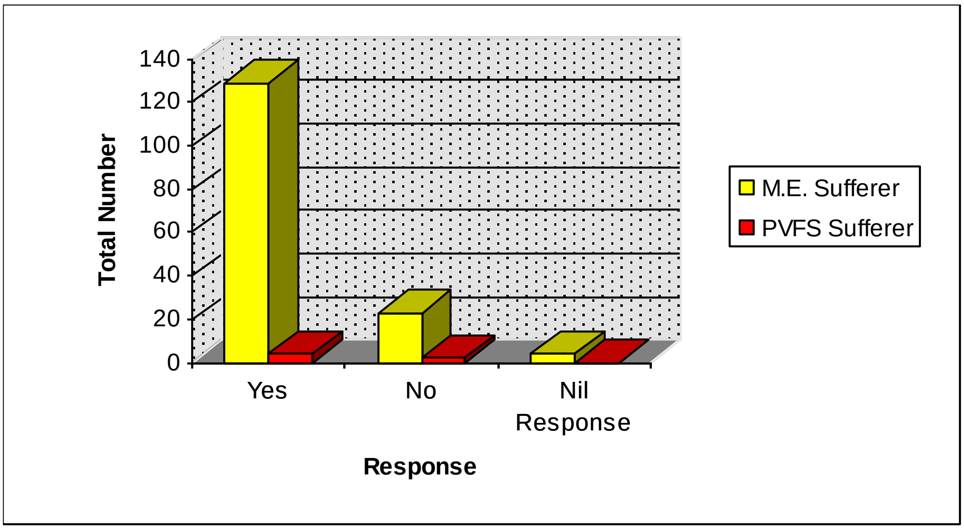


Response	M.E. Sufferer	PVFS Sufferer
Yes	50	0
No	102	6
Nil Response	4	0
Total	**156**	**6**

COMMENTS

- Unable to determine from 30.9% YES respondents the relationship between sufferer and colleagues/ relatives or friends as the questionnaire design did not allow for this data to be extrapolated.
- The majority of respondents 66.7% reported no known affected associates

Question 4 - Have you received any support or treatment since formal diagnosis?

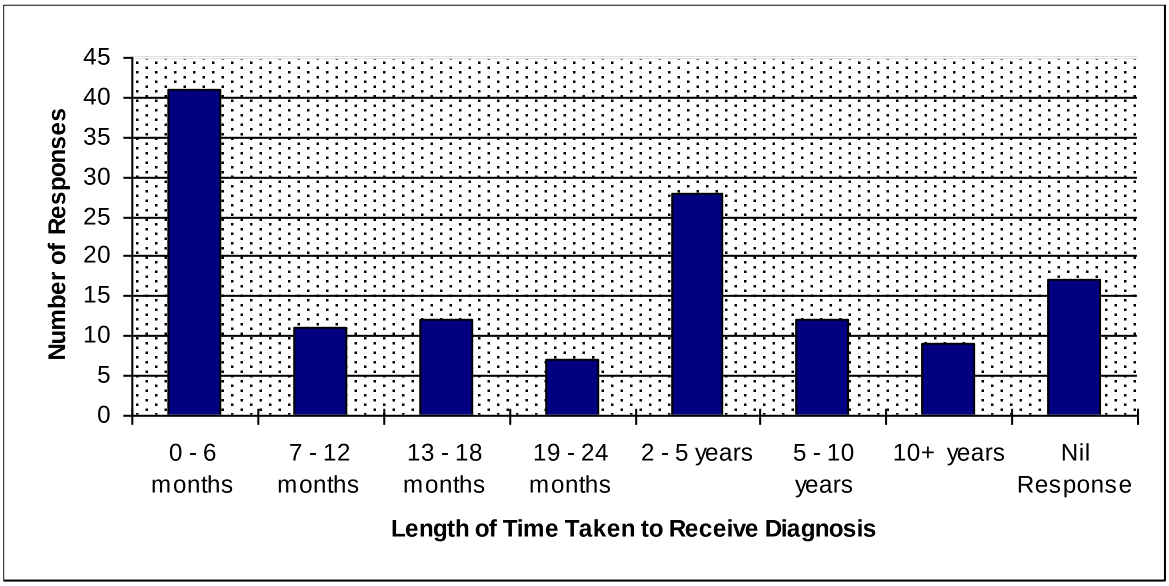


Category	Yes	No	Nil Response
M.E. Sufferer	129	23	4
PVFS Sufferer	4	2	0
Total	**133**	**25**	**4**

COMMENTS

- A higher number of respondents than expected (133 respondents) 82.1% stated they have received support or treatment since formal diagnosis with only 15.4% receiving none.

Question 5 - How long after you received formal diagnosis did you receive appropriate support and or treatment?



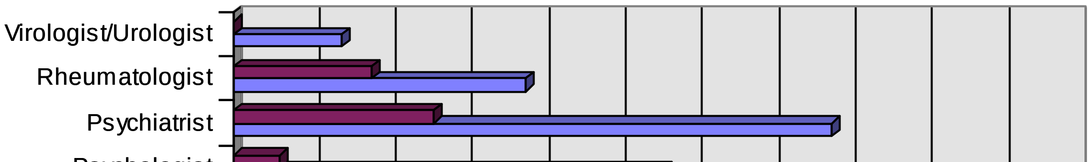
Length of Time Taken	Number of Responses
0 - 6 months	41
7 - 12 months	11
13 - 18 months	12
19 - 24 months	7
2 - 5 years	28
5 - 10 years	12
10+ years	9
Nil Response	17
Total	**137**

COMMENTS

- The average time taken to received support/treatment after formal diagnosis appears to be approximately 18.5 months.

- The majority of the respondents 30% (41 respondents) reported they had received treatment or advice between 0 - 6 months, followed by 20.6% who waited 2 - 5 years, 8.7% waited 5 - 10 years with a smaller percentage 6.5% waiting >10 years.

- 15.2% respondents reported having to wait >5 years after formal diagnosis to receive any support and or treatment with 35.8% waiting >2 years.



QUESTION 6 - Number of referrals by GP to out-patient clinics or in-patients

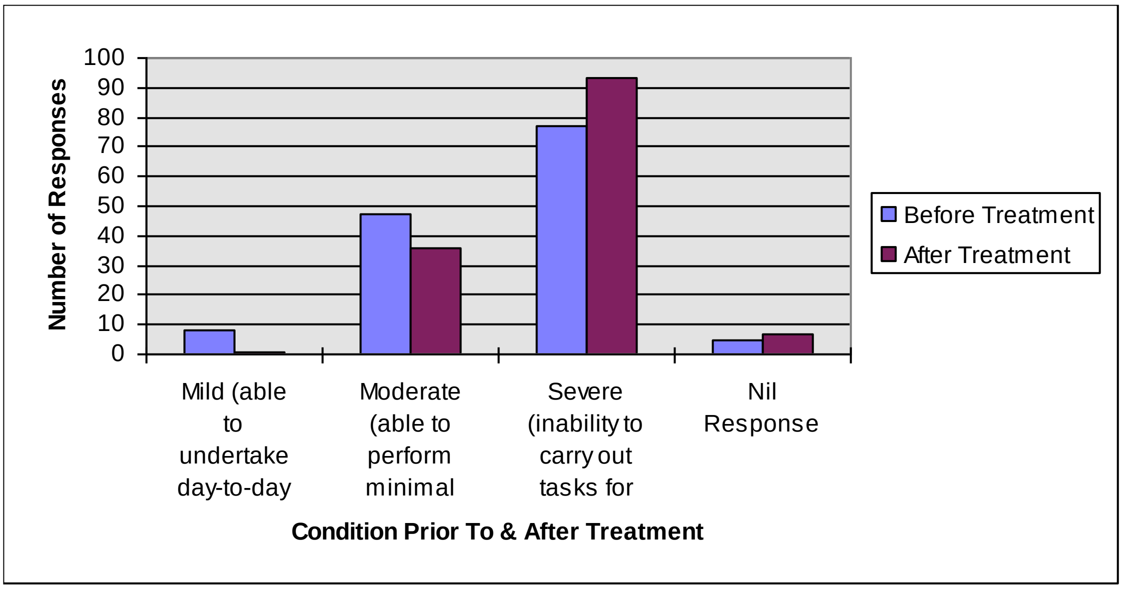
	Treatment Type	
Medical Discipline Referral	Out-Patient	In-Patient
Cardiologist/Gynaecology	3	0
Counsellor	22	3
Dietician	23	5
Endocrinologist	19	5
Ear, Nose & Throat	4	0
General Physician	37	14
Homeopathy/Osteopathy	21	1
Immunologist	31	5
Microbiologist	6	1
M.E. Specialist	37	5
Neurologist	51	21
Occupational Therapist	32	6
Paediatrician	0	4
Physiotherapist	42	8
Psychologist	28	3
Psychiatrist	39	13
Rheumatologist	19	9
Virologist/Urologist	7	0
Total	421	103

COMMENTS

- The three major referral disciplines for out-patient clinics appear to be the Psychiatrist/Psychologist (15.9%), Neurologist (12.1%) and Physiotherapist (9.9%). Whereas for in-patient (hospitalisation) these appear to be the Neurologist (20.3%), Psychiatrist/Psychologist (15.5%) and General Physician (13.7%). Cumulative responses appear to show a referral trend to Psychiatrist/Psychologist (15.8%) and Neurologist (13.7%) and to out-patient clinics rather than hospitalisation. This data appears not to support a proactive participation by the sufferer in his/her illness

- 25% of respondents recorded multiple responses when answering this question. 421 responses were collated for out-patient and 103 for in-patient referrals.

Question 7 & 8a - How would you consider your condition prior to and after treatment?



Condition Prior to Treatment	Before Treatment	After Treatment
Mild (able to undertake day-to-day tasks)	8	1
Moderate (able to perform minimal daily tasks)	47	36
Severe (inability to carry out tasks for oneself)	77	93
Nil Response	5	7
Totals	**137**	**137**

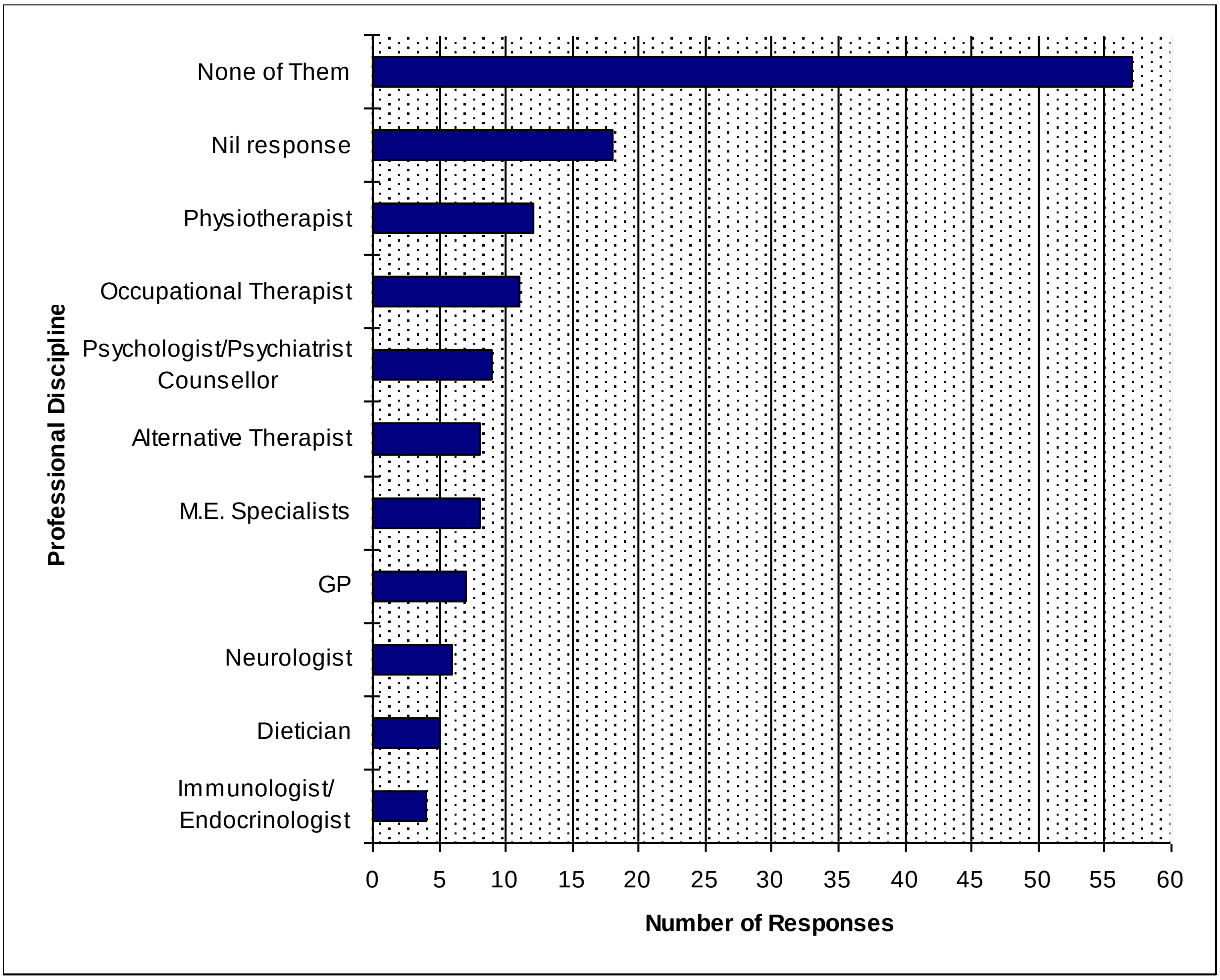
COMMENTS

- Responses reported for those identified **‘mild’** (8 to 1 respondent) appear to have improved after treatment (5.8% to <0.7%) which appears to be the case also for those identified **‘moderate’** (47 to 36 respondents) 34.4% to 26.3%.

- However, for respondents identified in the **‘severe’** category (77 to 93 respondents) there appears to be an increase 56.2% to 67.9%.

- It is unclear if the number of referrals to Psychiatrist/Psychologist (15.8%) Table 7, if non intrusive therapy was offered if this would result in reduced physical mobility for those identified under the **‘severe’** heading (56.2% to 67.9%) recorded

Question 8b - Which discipline was most beneficial/helpful?



Professional Discipline	M.E. Sufferers
Immunologist/ Endocrinologist	4
Dietician	5
Neurologist	6
GP	7
M.E. Specialists	8
Alternative Therapist	8
Psychologist/Psychiatrist/Counsellor	9
Occupational Therapist	11
Physiotherapist	12
Nil response	18
None of Them	57
Total	145

COMMENTS

- A few respondents recorded multiple answers for this question. A total of 145 responses were collated. A high percentage 39.3 % of respondents (57 responses) reported none of the professional disciplines referred to were beneficial/helpful. 12.4% did not answer this question. The top five disciplines (Table 9) 8.2% Physiotherapist, 7.5% Occupational Therapist, 6.5% Psychologist/Psychiatrist/Counsellor, 5.5% Alternative/Complementary Therapist & M.E. Specialist appear to have provided some benefit/help to sufferers referred.
- A significant and unexpected finding was only 8 (Table 9) out of 42 respondents (37 out-patients 5 in-patients) (Question 6) felt referral to an M.E. Specialist was **'beneficial or helpful'.**

Question 9 - If your condition deteriorated after referral, do you attribute this to anything specific?

Attributory Factors	Number of Responses
Nil Response	48
Overdoing It/Graded Exercise	26
Inappropriate Advice/Lack of illness Understanding	14
Nothing Specific	13
Reaction to Other Prescribed Medication	12
Antidepressants	10
Physiotherapy	8
Travel to and from Treatment Centre	4
Stress/Depression/Trauma	4
Lack of Support	4
Alternative Therapy / Remedies	4
Unsuitable Treatment Environment	3
Cognitive Behavioural Therapy	3
Occupational Therapy	2
Counselling	1

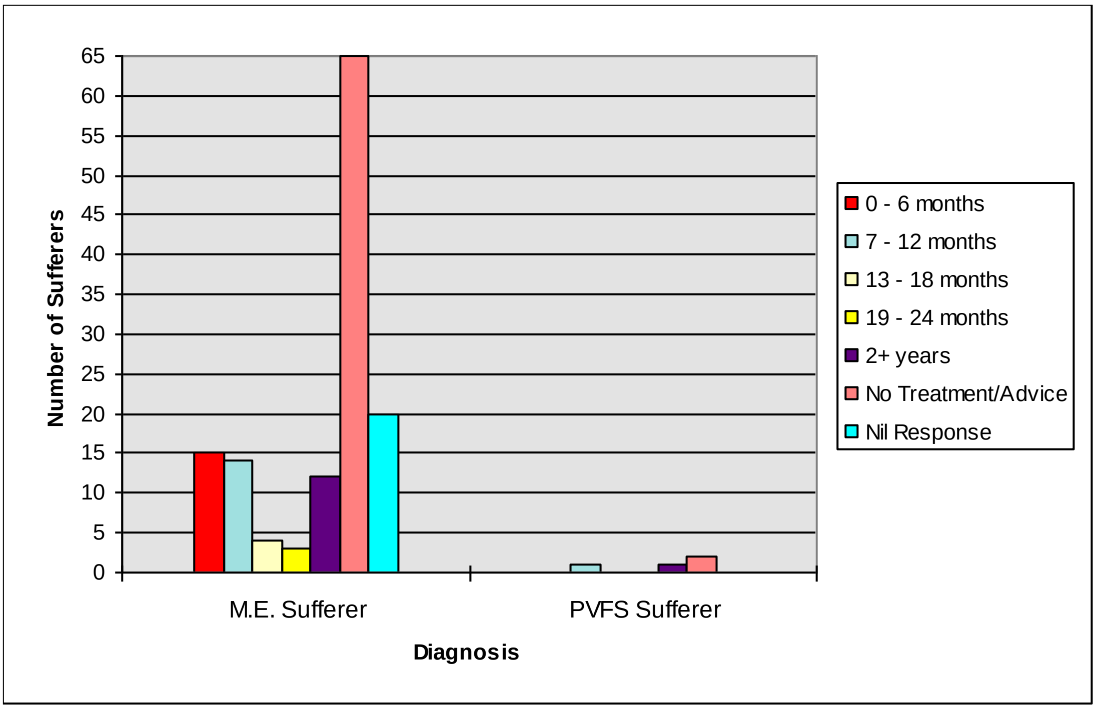
COMMENTS

- Significantly higher numbers of respondents perceived **'Overdoing it/Graded Exercise'** (16.6%) over all other attributory factors followed by 8.9% inappropriate advice, 7.6% reaction to other prescribed medications, 64.% antidepressants and 5.1% physiotherapy.

- Reported previously for Question 6, 'number of referrals and medical discipline type' where respondents were referred to, physiotherapy 9.9% in-patient (hospitalised), 7.8% out-patients, occupational therapy 5.8% in-patients (hospitalised) and 7.6% out-patient clinics and may provide and explanation for the above. Although responses in Question 8b could not support this.

- A total of 156 responses were collated as many respondents provided multiple responses for this question

Question 10 - Were you monitored or followed up after treatment, state period if Yes?



Follow Up Period	M.E. Sufferer	PVFS Sufferer
0 - 6 months	15	0
7 - 12 months	14	1
13 - 18 months	4	0
19 - 24 months	3	0
2+ years	12	1
No Treatment/Advice	65	2
Nil Response	20	0
Totals	**133**	**4**

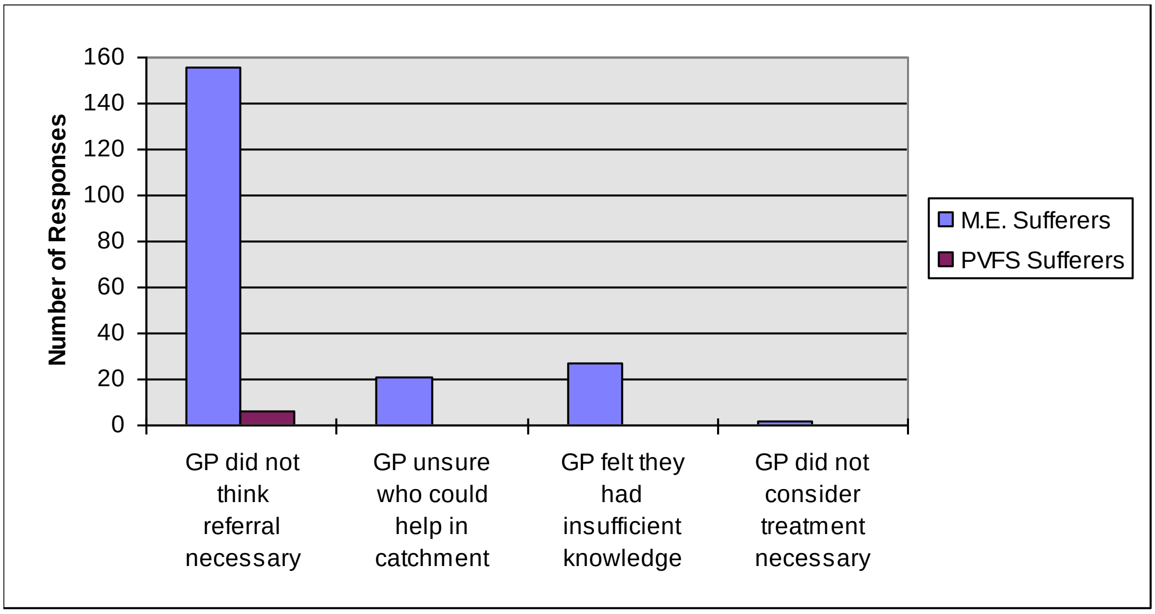
COMMENTS

- 14.6% of the respondents did not record a response for this question. From the data collated only 36.5% were monitored after treatment against 48.9% with no follow up. It is not possible to determine from the date what type of follow up or treatment regime was provided as the questionnaire design did not allow for this type of data to be collected.

- 60% of respondents reporting the length of time take to receive **'follow up monitoring'** ranged from 0 - 12 months (30% 0-6 months & 30% 7-12 months. 8% waited 13-18 months with a smaller number (6%) waiting 19-24 months.

- It appears 26%, which is a significant percentage of the total number of respondents (13 out of 50 respondents) waited >2 years to received follow up monitoring and or treatment.

Question 11 - If you have not received treatment or advice since formal diagnosis, do you attribute this to any of the following?



Lack of Diagnosis/Advice	**M.E. Sufferers**	**PVFS Sufferers**
GP did not think referral necessary as no treatment available	156	6
GP unsure who could help in catchment area	21	0
GP felt they had insufficient knowledge to treat you	27	0
GP did not consider treatment necessary or desirable	2	0
Total	206	6

COMMENTS

- >28% of respondents gave multiple responses to this question, in total 206 responses were collated.
- 76.5% of respondents, which is a significant percentage of the total number of responses collated (162 out of 206) perceived their **'GP did not think referral necessary as no treatment available'**, with 12.7% respondents perceiving GP having insufficient knowledge to treat them.
- 9.9% thought their GP was unsure of who (professional discipline) could help in the catchment area while <1% (0.9%) thought the GP did not consider treatment necessary or desirable.
- It is evident that on the whole M.E. sufferers do not feel confident the GP has sufficient knowledge about the illness and or, which medical discipline referrals should be made in the first instance.
- Caution must be considered as data collated is primarily based on M.E. sufferers perception of GPs intentions and knowledge, therefore is speculative and cannot be validated.

Question 12 - Which of the following diagnostic tests have you received?

DIAGNOSTIC TESTS

DIAGNOSTIC TESTS TYPE	
Type	**Responses**
Blood Tests	112
Psychiatric Assessment	53
MRI Scan	45
Allergy Test	29
Brain Scan	29
E.C.G	21
Blood Pressure	20
Lumbar Puncture	19
Stamina Test	11
Nil Response	10
Muscle Strength/Biopsy	6
SPECT or PET Scan	6
Food Intolerance	1
Light Sensitivity	1

BLOOD TESTS TYPE	Number of Responses
Thyroid	32
Infectious Diseases Various	25
Virology	10
Cholesterol	9
Diabetes	9
Haematology	8
Rheumatology	7
Hormones	6
B12	5
Arthritis	3
HHV6	1
Blood Count	20

Blood Pressure Position Taken	Number of Responses
Standing	15
Sitting	18

Stamina Type Tests	Number of Responses
Treadmill	3
Bike	3
Unknown	5

COMMENTS

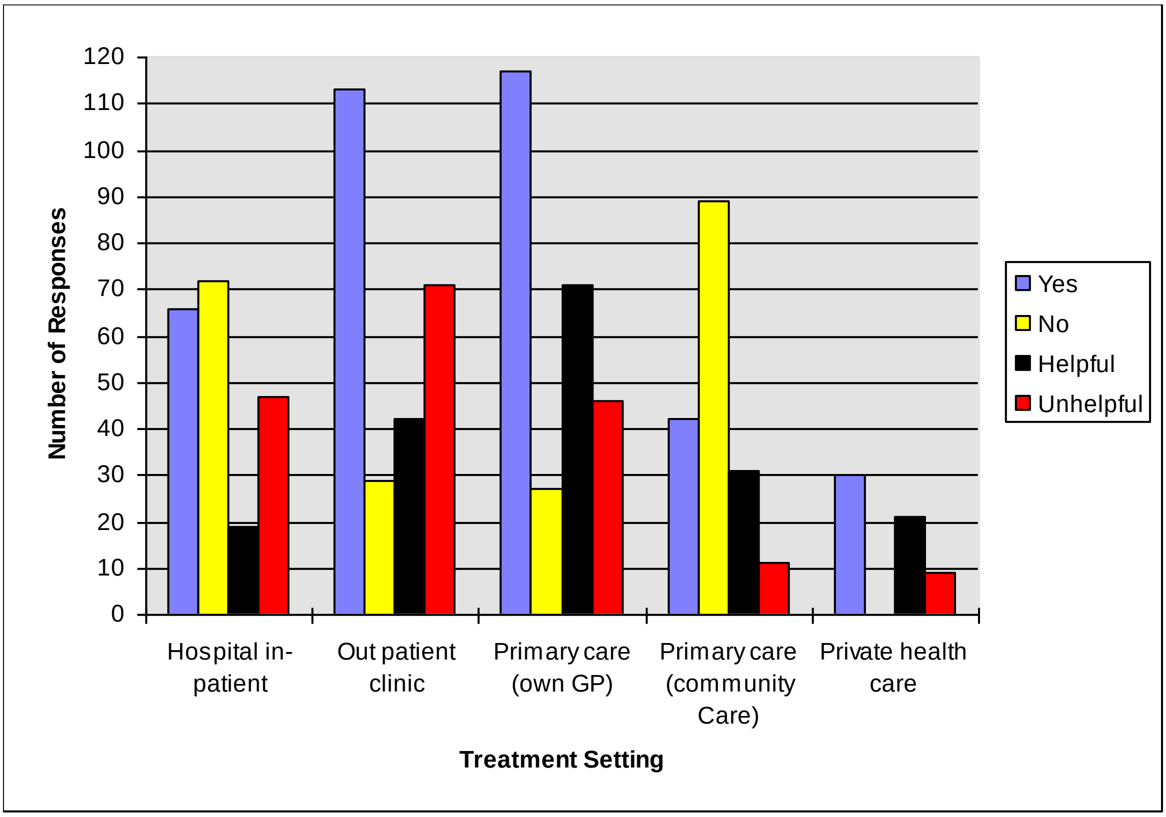
- >55% of respondents for heading **'test type'** gave multiple responses and in some cases >2+ responses were provided, which account for the high number of responses received for this section (363 responses collated).
- 30.9% (112 respondents) gave blood samples, which is not significant as many ailments are diagnoses from blood test results. 14.6% (53 respondents) underwent psychiatric assessment, which confirms referral rate Question 6 '**referrals'** 15.9% and 15.5% (out-patients and in-patient referrals).

- 12.4% had an MRO Scan, 7.9% had allergy tests and brain scans with a small percentage 1.7% having SPECT or PET Scans and Muscle Strength/Biopsies with 0.3% being tested for food intolerance or light sensitivity.

- From the 5.5% whose blood pressure was taken, 45.5% were standing and 54.5% were seated. 11 (3%) respondents received stamina tests, 3 were tested on a treadmill and bike with 5 stating **'test type unknown'**.

- The range of Blood test types reported by respondents range from 23.8% thyroid, 18.5% infectious disease, 7.4 virology, 6.7% diabetes and cholesterol, 3.5% B12 deficiency, 2.2% arthritis.

Question 13 - In what setting have you received treatment or advice and what did you experience?



	Responses			
Setting	**Yes**	**No**	**Helpful**	**Unhelpful**
Hospital in-patient	66	72	19	47
Out patient clinic	113	29	42	71
Primary care (own GP)	117	27	71	46
Primary care (community Care)	42	89	31	11
Private health care	30	0	21	9
Totals	**368**	**217**	**184**	**184**

TREATMENT/CARE RATINGS OF EXPERIENCE

Rating Scale 1= (excellent) to 5 (poor)

Treatment/care ratings of experiences												
	Helpful						**Unhelpful**					
Care Settings	1	2	3	4	5	Nil Response	1	2	3	4	5	Nil Response
Hospital in-patient	2	1	7	7	1	1	3	4	4	3	28	5
Out patient clinic	3	8	16	6	5	4	6	5	4	12	36	8
Primary care (own GP)	13	13	23	11	5	6	3	2	3	12	19	7
Primary care (community Care)	5	8	9	6	1	2					11	
Private health care	2	5	3	5	3	3					7	2
Totals	**25**	**35**	**58**	**35**	**15**	**16**	**12**	**11**	**11**	**27**	**101**	**22**

COMMENTS

- Respondents provided multiple responses for both out-patient and in-patient settings as a large number had received care by more than one service provider and or attended more than one medical discipline to obtain various test which can be seen in Question 12.

- 25.5% respondents appear to view hospitalisation as unhelpful a similar view held of out-patient clinics 38.7% supported by the majority of respondents by a rating scale of 5.   Primary care settings reported the opposite with 38.7% (own GP) and 16.8% (community care) were perceived as helpful and supported by a rating scale of ‘3’ **‘experiences scale’**.

- In the main treatment and support is undertaken under the responsibility of the GP (117 respondents). The majority of respondents (49 out of 71) appear to suggest from the **‘rating scale’** the treatment and care provided by the GP ranges from ‘excellent’ to ‘average’ (ratings 1 - 3).

- Private health care. The respondents who reported seeking private health care included those who sought treatment and advice from M.E. Specialist Teams, Complementary & Alternative Therapies, Counselling and General Care to assist with day to day essential tasks, such as washing and cooking.

- Hospitalisation (in-patient) treatment and care appears to be received less favourably by the majority of respondents although this is difficult to qualify due to the number of respondents who provided >2+ answers. However, from the data collated hospital in-patient and out-patient clinics (28 and 36 respondents) received a higher rating than other care settings of 5 (poor & unhelpful).

- Overall it appears no one care setting can be identified as providing care and treatment which is felt effective, helpful or useful as perceived by M.E. sufferers.

Question 14 - If you received treatment as a hospital in-patient/out-patient how do you feel about your experience, treatment and surroundings?

How do you feel about your experience, treatment and surroundings?		
Staff/Health Professional Knowledge of Illness	**In-Patient**	**Out Patient Clinic**

Average Knowledge	8	15
Excellent Knowledge	6	23
Limited Knowledge	22	38
Nil Response	10	13
No Knowledge at all	38	30

Attitude of Staff/Health Professional Towards You	In-Patient	Out Patient Clinic
Hostile/Rude/Aggressive/Felt Humiliated & Frightened	14	6
Nil Response	11	18
Received minimal support and care	31	40
Suggested illness and symptoms were psychological	31	23
Unsupportive and uncaring	35	27
Very supportive and caring	12	30

Surroundings	In-Patient	Out Patient Clinic
Extremely noisy and busy	48	40
Nil Response	12	26
Overheated with bright lights	42	40
Quiet and relaxed	13	32
Stressful	43	52
Long waiting times to see consultant	0	5
Transport/Long Journey to hospital is unhelpful	0	3

COMMENTS

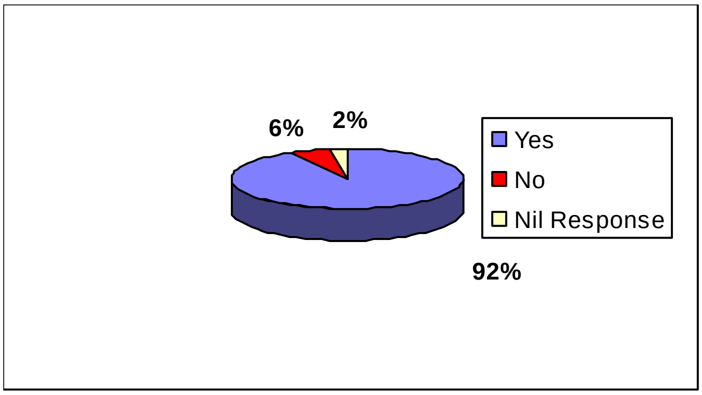
- An unexpected finding was the number of respondents who perceive health professionals at out-patients clinics (63.8%) have more knowledge of this illness than in-patient (42.9%) (hospitalisation) health professionals.

- Responses collated under the heading **‘staff/health professional knowledge of this illness’** for out-patient and in-patient M.E. sufferers perceived ‘average knowledge’ 12.6% against 9.5%, ‘excellent’ 19.3% and 7.2%, ‘limited knowledge’ 25.2% against 26.2%. A significant difference appears in the category ‘no knowledge at all’ out-patient (25.2%), in-patient (45..2%).

- A similar trend is found under the heading **’Attitude of Staff/Health Professionals towards Sufferer’** in particularly, category ‘supportive and caring’ 20.9% (out patients) against 8.9% (in-patient). This finding may not be surprising when considering data collated for heading ‘suggested illness and symptoms were psychological’ 15.9% (out-patient) against 23..2% (in-patient) and may explain why sufferers perceive hospitalisation experiences as unsupportive and uncaring (26.1%), received minimal support and care 23.2% and felt humiliated, scared and thought staff were hostile, rude and aggressive towards them 10.4%.

- Surrounding A higher number of respondents appear to have experienced out-patient clinics more quite and relaxed than in-patient stays (17.9% and 8.2%). Sufferers appear to have no input into ‘surrounding conditions’ which they perceive is detrimental to there well-being, such a noise, bright lights, overheating and busy environment. 38 respondents did not complete this section
- Sufferers perception of treatment (Question 13) and experiences (Question 14) from the data collated does not provide a very positive image of health care professionals and settings based on the information provided from this survey only.

Question 15, 16 & 17- Have you ever tried any complementary/alternative therapies? If Yes, state reasons and type and did any help your M.E.?



Question 15	
Response	Number of Responses
Yes	149
No	9
Nil Response	4
Total	162

COMMENTS

A significant number of respondents 91.9% reported having sought help from complementary therapies compared to a small number 5.6% who had not. The data as collated appears to suggest sufferers perceive conventional treatment/therapy is inappropriate or lacking. Findings from Question 16 & 17 supports the view sufferers felt desperate and would try anything that might help (12.6%) with 15.6% reporting no treatment or support had been offered by GP or other health professional.

Question 16 - Reason For & Type of Alternative Therapies Tried?	
Reasons	Number of Responses
Felt Desperate and would try anything that may help	105
Herbal Treatments	95
Homeopathy	90
No treatment/support offered by GP	68
Reflexology	63
No treatment/support offered by Health Professionals	62
Acupuncture	60
Osteopathy	55
Aromatherapy	53
Massage	48
Support from other ME sufferers	48
Meditation/Faith Healing	29
Yoga	29
Nutrition/Dietary Changes	9
Magnet/Tens Therapy	8
Reiki	7
Chiropractor/Crystal Healing	6

Question 17 - Did any of the alternative therapies help, if so which type?	
Treatment Types	**Number of Responses**
Nothing Helped	76
Osteopathy	14
Herbal Treatments	14
Meditation/Faith Healing	11
Nil Response	10
Massage	10
Homeopathy	9
Nutrition/Dietary Changes	8
Acupuncture	7
Reflexology	6
Aromatherapy	6
Yoga	4
Support from other ME Sufferers	4
Reiki	4
Magnets	1

COMMENTS

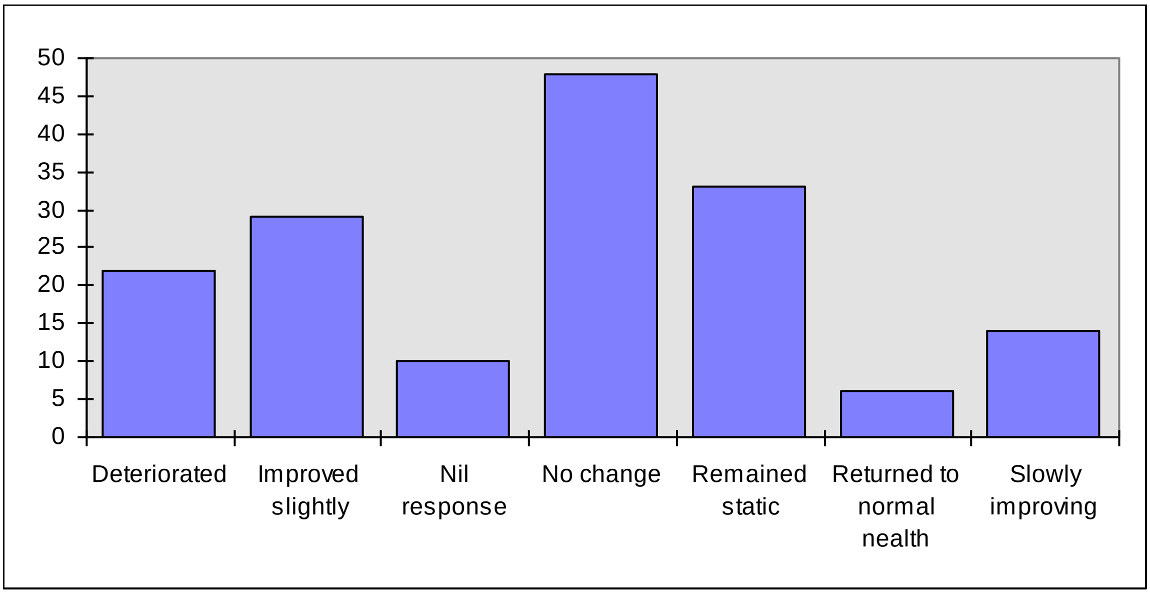
- Question 16 & 17 Sufferers in the main reported seeking help from complementary therapies for two main reasons, feeling desperate 12.6% and because they were receiving no care/treatment from other health professionals (conventional medicine) 15.6%.

- The complementary therapies mostly tried appear to be herbal treatment 11.4%, homeopathy 10.8%, reflexology 7.5%, acupuncture 7.2%, osteopathy 6.6%, aromatherapy 6.3%, massage 5.7%.

- Helpfulness 41.3% reported none of the therapies tried were helpful. From the therapies tried the top six identified were osteopathy and herbal treatment 7.6%, meditation/faith healing 5.9%, massage 5.4%, homeopathy 4.9% and nutrition/dietary changes 4.3%.

- From additional comments submitted 8 respondents stated low dosage of antidepressants were of great benefit, although antidepressants were not recorded in the table of helpful therapies. One explanation for this may be respondents view antidepressants as a conventional treatment rather than complementary therapy.

Question 18 - State how you feel your condition changed? If returned to normal state for how long and if you have resumed all work/duties as was the case prior to illness?



Condition Criteria	Number of Responses
Deteriorated	22
Improved slightly	29
Nil response	10
No change	48
Remained static	33
Returned to normal health	6
Slowly improving	14
Total	162

COMMENTS

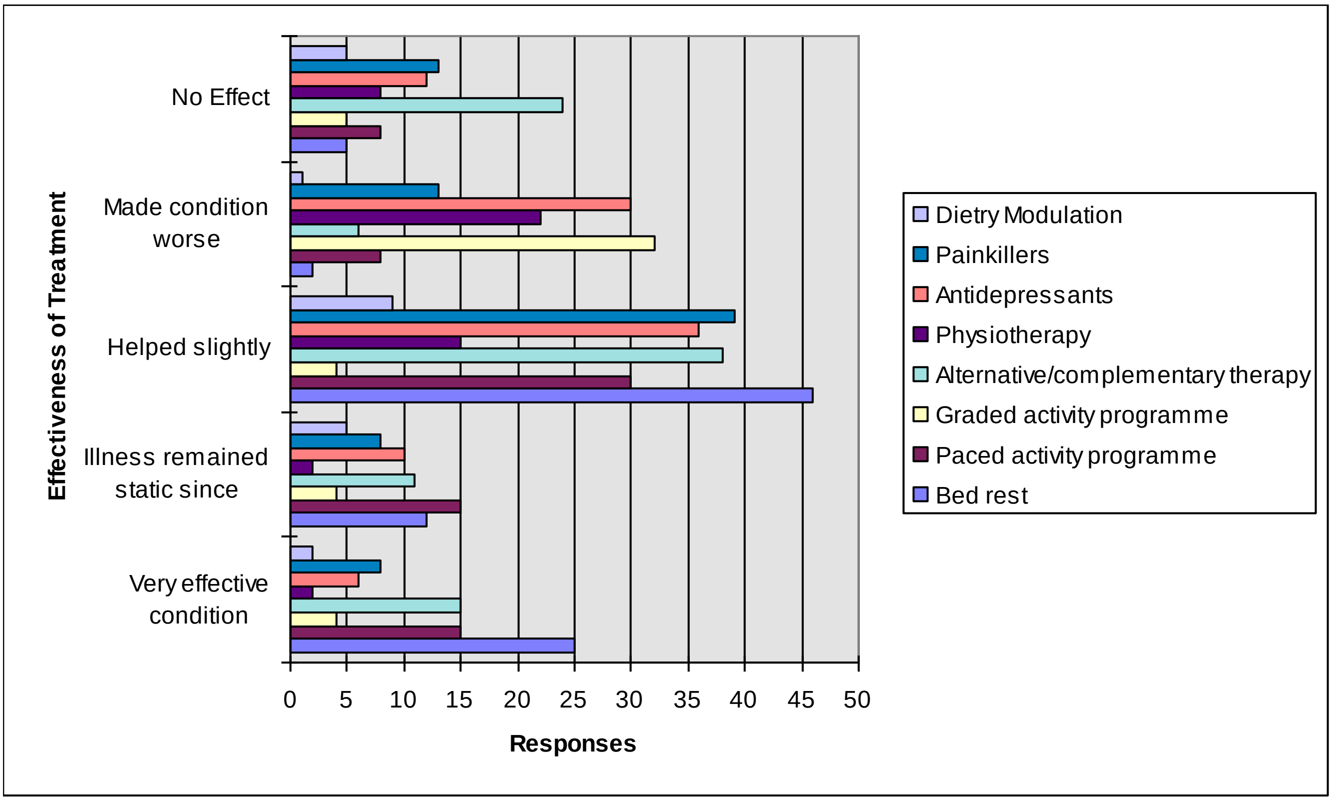
- Of the 6 respondents (3.7%) whose condition returned to '**normal health'** none reported there condition improved sufficient to allow them to resume all work/duties as was the case prior to illness. The period of 'normal health' varied from 6 - 24 months (2 x 0-6 months; 7-12 months & 19-24 months).

- Statement provided by the 6 respondents on' **treatment/aids'** they considered effective in their recovery included - pacing self, practical support and help, dietary change, undertaking neuro-linquistic programme (1 respondent only), using knowledge and information from other ME sufferers.

- It is unclear of the 20.4% (condition remained static) if there condition would have improved or deteriorated had the use complementary therapies not been tried while taking into account the 8.6% reported condition '**slowly improving'** with 17.9% reporting **'improved slightly'**.

- Comparing data collated above and that of the 19.6% (48 respondents out of 162) whose condition did not change against 13.6% (22 respondents out of 162) whose condition deteriorated it appears complementary therapies in the main do not have a major deterioration impact on physical well-being.. From the data collated in Question 16, 17 & 18 it appears M.E. sufferers are making and attempting to regain well-being by pro-active decision making and direct action.

Question 19 - Have you or are you currently on any treatment programme or medication? If Yes, how do you consider their effectiveness?



Treatment/medication	Very effective condition improved	Illness remained static since starting treatment	Helped slightly	Made condition worse	No Effect
Alternative/complementary therapy	15	11	38	6	24
Antidepressants	6	10	36	30	12
Bed rest	25	12	46	2	5
Dietary Modulation	2	5	9	1	5
Graded activity programme	4	4	4	32	5
Paced activity programme	15	15	30	8	8
Painkillers	8	8	39	13	13
Physiotherapy	2	2	15	22	8
Total	**77**	**67**	**217**	**114**	**80**

COMMENTS

- The most popular effective treatment/programme which appears not to have any detrimental effect on physical deterioration is bed rest 32.5% (condition improved), paced activity programme 22.5% (remained static) and bed rest 21.2% (helped slightly).

- Graded exercise programmes (28%), antidepressants (26.3%) and physiotherapy (19.3%) are recorded as the three main treatment types causing condition deterioration. Painkillers (17.9%) and bed rest (21.2%) have the highest recorded number of respondents stating these helped slightly.

- Written comments from respondents painkillers were taken to reduce pain and assist sleep. Antidepressant use was stated by 28 respondents aid sleep pattern. The most popular prescribed antidepressant was Amitriptyline (33.8%)

Analysis of Antidepressants Prescribed

- There appears to be an equal rate for prescribing ‘SSRI’ and ‘tricyclic’ antidepressant compounds.

- The three frequently prescribed SSRI antidepressants appears to be Fluoxetine (Prozac - brand name) 18%, Paroxetine (Seroxat - brand name) 15.8% and Lustral 12% and for ‘tricyclic’ antidepressants Amitryptiline 33.8%, Dothiepin 7.2% and Carbamazepine 3.6%.

- The responses for prescribed antidepressant compounds is not uncommon although one would have expected to find a higher response rate for newer SSRI’s which are recorded as having fewer side effects.

Question 20 - What was your occupation, if any when you became ill?

Occupation	Number of Responses
Secretarial/Administrative	31
Student/Pupil	29
Lecturer	24
Nursing/Carer	15
Manual Worker	14
Housewife/Mother	13
Professional Discipline	7
Researcher/Technician (Medical)	6
Accountant/Bank Employee	6
SEN/classroom assistant	5
Social Worker (CEW)	5
Information Technologist	4
Psychologist/Counsellor	3

COMMENTS

- Regards to employment, the three main risk groups appear to be secretarial/administrative 31 (19.2%), student/pupil 29 (17.9%), Lecturer 24 (14.9%). It is unclear if ‘education’, ‘educational environments’ or ‘stress factors’ have a contributory factor for this category. What is interesting is that the ‘education category accounts for >33% of the total number of responses.

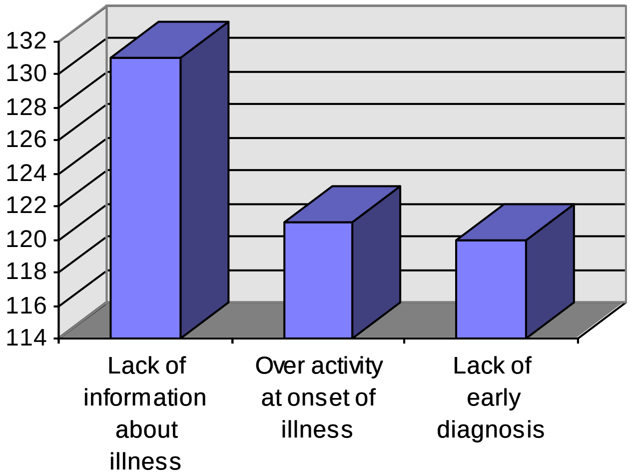
- All recorded employment categories themselves reflect stress factors, albeit at different rates and levels. All responses are based on M.E. sufferers ‘perceived’ illness onset and not during or after receiving formal diagnosis.

Question 21 - What factors, if any, do you consider may have precipitated/ contributed to your chronicity?

Factors	Number of Responses
Lack of information about illness	131
Over activity at onset of illness	121
Lack of early diagnosis	120
Lack of practical support	102
Stressful working environment/job	73
Antibiotics	30
Antidepressants	25
Working with chemicals	22
Graded exercise programmes	21
Depression	13
Cognitive behavioural therapy	10
Physical/mental stress/trauma	8

COMMENTS

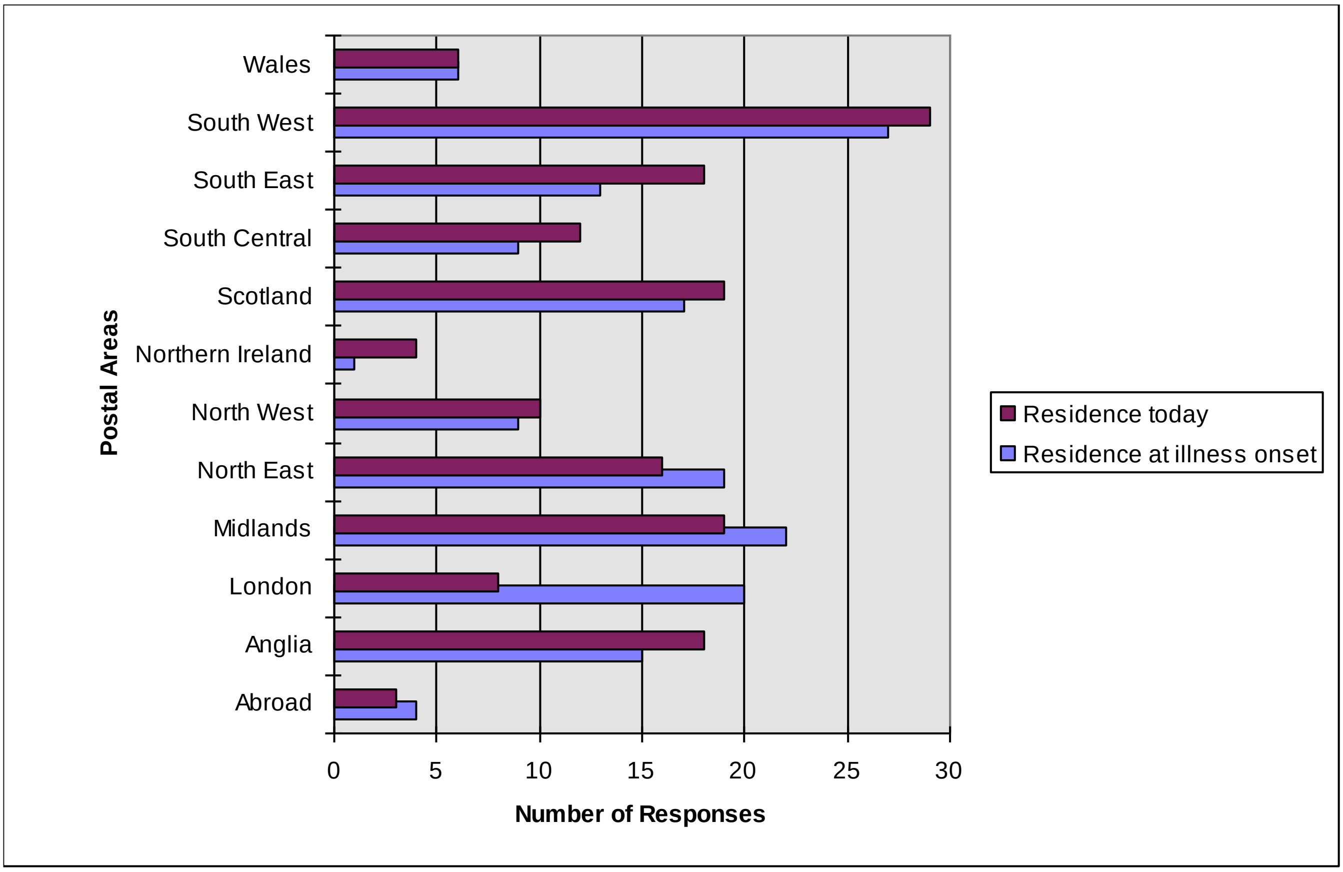
- The top three factors ‘lack of information about illness’ 19.5%, ‘over activity at onset of illness’ 17.9% and ‘lack of early diagnosis’ 17.8% appear to be linked to lack of information on aetiology, causation and treatment, and as such the findings are not surprising. Similar findings were reported for Question 9.



- An unexpected finding was the responses received for factors ‘stressful working environment/job’ 10.8%, ‘working with chemicals’ 3.2% and depression 1.9% as none of these were identified by respondents as attributory factors for condition deterioration (Question 9)

- 15.0% of respondents stated ‘lack of practical support’ (Table 21) contributed to their chronicity, although a smaller number 2.5% (Question 9) thought it contributed to condition deterioration. An explanation for the large differences in responses may be due to respondents’ perception differences for ‘condition deterioration’ and ‘chronicity’ which should not be underestimated.

Question 22 - 24 - Place of residence when first became ill & residence today



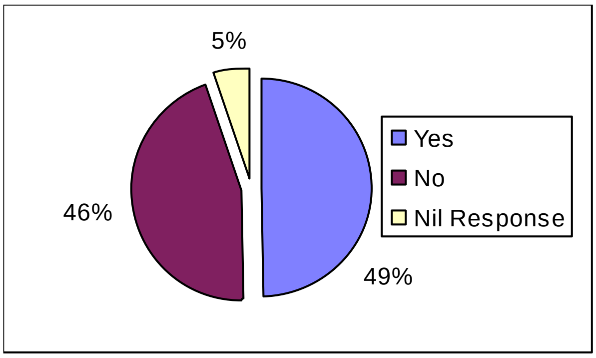
Postal Area	Residence at illness onset	Residence today
Abroad	4	3
Anglia	15	18
London	20	8
Midlands	22	19
North East	19	16
North West	9	10
Northern Ireland	1	4
Scotland	17	19
South Central	9	12
South East	13	18
South West	27	29
Wales	6	6
TOTAL	**162**	**162**

COMMENTS

- The percentage of respondents in the different regions range from 17.3% in South West to 1.5% Northern Ireland. (Table 22) Interestingly the number of respondents residing in 'South West' and 'Midlands' remains in first and second place for 'residence at illness onset' 16.7% and 13.6% and 'residence today ' 17.9% and 11.7% (Scotland shares second place with 11.7%).

- The top five **'residence at illness onset'** appear to be South west 16.7%, Midlands 13.6%, London 12.3%, North East 11.7% and Scotland 10.6%. This picture changes when compared against **'residence today'** top five are South west 17.9%, Midlands and Scotland 11.7%, South East 11.1% and North East 9.9%. A full list of post code areas within each region can be found in Appendix 1.

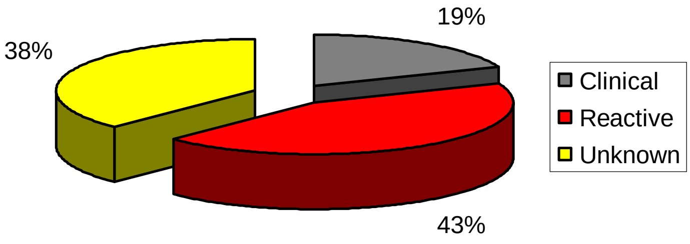
Question 25 & 26 - Have you suffered from depression? Was this clinical or reactive depression and when were you suspected/diagnosed?



Question 25 - Have you ever suffered from depression?			
Criteria	Yes	No	Nil Response
Number of responses	80	74	8

QUESTION 26

Question 26 Type of Depression Diagnosed			
Criteria	Clinical	Reactive	Unknown
Number of Responses	15	35	30



COMMENTS

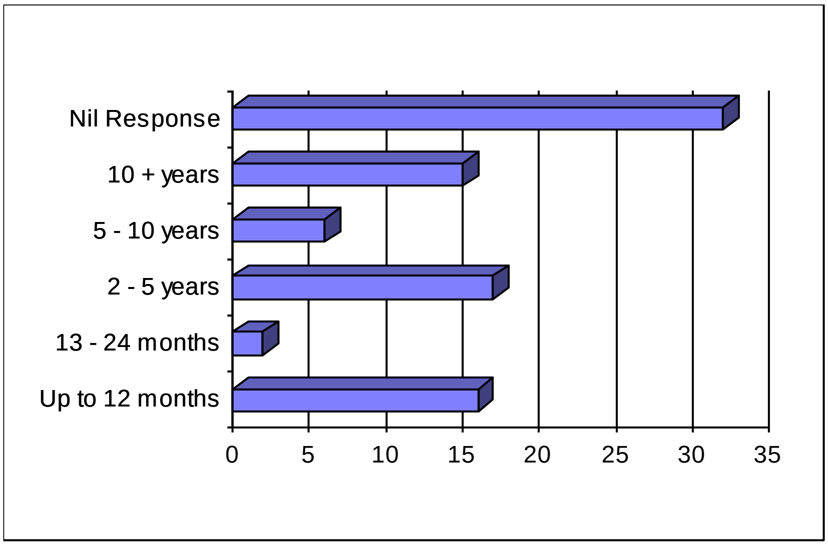
- From the 154 respondents who replied 52% reported having suffered from depression against 48% who had not is on the whole equal. 8 respondents (8 out of 162) did not respond.

- A higher number of respondents 43.7% reported suffering from 'reactive' depression against 18.7% with a diagnosis of clinical depression. However, the 37.6% 'unknown' could change the percentage in either direction. The findings are not surprising when taking account findings recorded for questions 8b, 9, 13 and 14.

Question 27 - If YES to Q25, when and for how long and do you still suffer from depression?

Question 27 - When were you diagnosed?	
Criteria	**Number of Responses**
Before you suffered from M.E.	34
After/during M.E.	54
Suspected as suffering from depression	17
Diagnosed as suffering from depression	26
Total	**131**

Length of Depression (months/years)



Length of Depression	Number of Responses
Up to 12 months	16
13 - 24 months	2
2 - 5 years	17
5 - 10 years	6
10 + years	15
Nil Response	32
Total	88

Do you still suffer from depression?

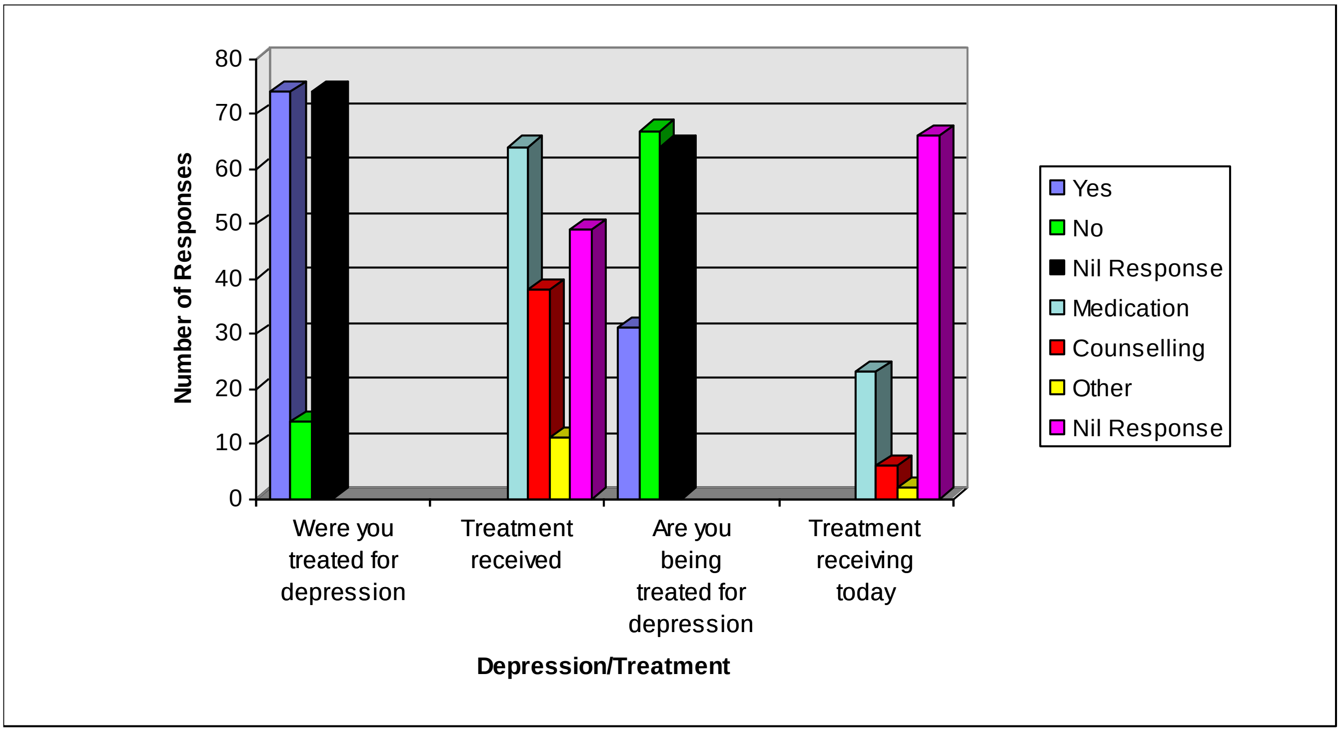
Do you still suffer from depression	Number of Responses
Still suffers from depression	42
Does not suffer from depression	40
Nil Response	6

COMMENTS

- 8 respondents identified for Question 25 & 26 as ‘nil responses’ completed this section of the questionnaire, which accounts for the increased number of responses recorded. In addition, respondents under the heading **‘when diagnosed’** provided secondary responses 17 respondents declared they were suspected as suffering from with 26 being diagnosed with depression before and after M.E. diagnosis.

- The period 2 - 5 years represents the most frequently recorded duration time 30.4%. This finding is not surprising when considering the findings in Table 6 which recorded 20.6% of respondents waiting 2 - 5 years for a formal diagnosis. Longevity and chronicity of this illness may be a key factor for extended periods of depression and may provide an explanation for the finding ‘do you still suffer from depression’. The findings are not surprising when considering the longevity, chronicity, treatment and care findings recorded throughout this survey.

Question 28 (a) & (b) - Were you and are you being treated for depression, state treatment type?

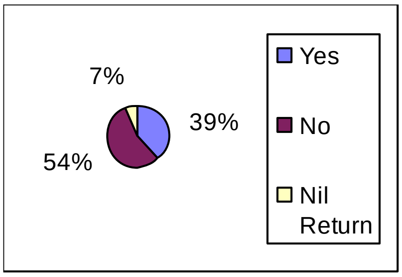


Criteria	Were you treated for depression	Treatment received	Are you being treated for depression	Treatment receiving today
Yes	74		31	
No	14		67	
Nil Response	74		64	
Medication		64		23
Counselling		38		6
Other		11		2
Nil Response		49		66
Totals	162	162	162	97

COMMENTS

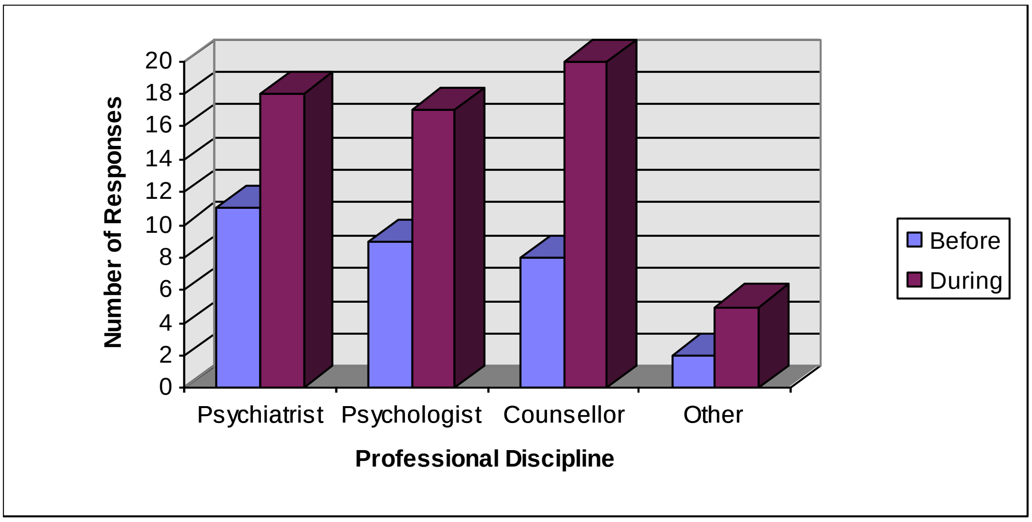
- For those treated with depression 84.0% and those being treated 56.6% the preferred treatment type is ‘medication in both conditions 56.6% and 74.2% followed by counselling 33.6% and 19.4%. The responses received under the heading **‘were you treated for depression’** a large majority of respondents gave multiple responses for treatment type (medication and counselling was the most popular). It appears for those who suffer from depression and have a formal M.E. diagnosis are receiving only one form of treatment type (medication, counselling or other). No information was provided on type of treatment or medication for **‘other’** heading.
- A large number of respondents failed to provide a response for each heading ‘were you treated for depression, 49 and 66 against ‘are you being treated for depression.
- A small number of respondents (23 our of 162) who completed the survey have declared they are suffering from depression although this figure may be higher when taking into account 66 respondents failed to respond to this question.
- It should also be noted that 28 respondents in Question 18 & 19 claimed the use of ‘Amitryptiline’ was prescribed to assist sleep pattern.

Question 29 - Have you ever received treatment for any psychological problems?



Criteria	Number of Responses
Yes	63
No	88
Nil Return	11

Question 30 - If YES, to Q29 when was this and who treated you?



Professional Discipline	Before Diagnosis	During M.E.
Psychiatrist	11	18
Psychologist	9	17
Counsellor	8	20
Other	2	5
Total	30	60

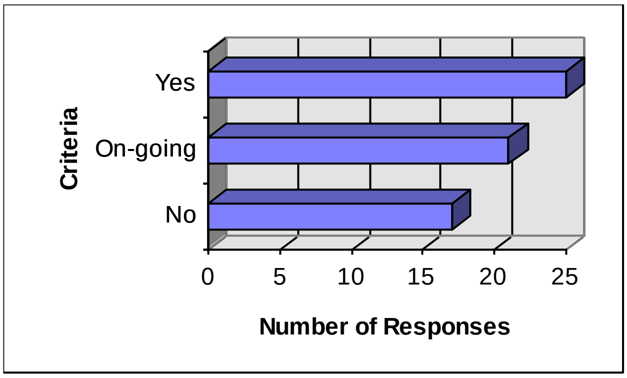
COMMENTS

- 38.9% declared having suffered from psychological problems, 54.3% declaring none.

- Overall there is little difference between the professional disciplines in providing treatment psychiatrist 32.2%, psychologist 28.9% and counsellor 31.1%. No additional information was provided by those who stated ‘other’ 7.8%.

- It is interesting before to receiving an M.E. diagnosis 36.6% were treated by the psychiatrist which dropped to 30.0% after diagnosis, although an overall increase in the number of respondents being seen by 2+ professional disciplines (psychiatrist and counsellor or psychiatrist and psychologist) increased during M.E. (after diagnosis).

Question 31 - Were all issues resolved during this period?



Criteria	Number of Responses
No	17
On-going	21
Yes	25
Total	63

COMMENTS

- A high percentage 27% of respondents appear to have unresolved issues which have and or were not treated during time spent with a mental health professional (psychiatrist, psychologist or counsellor). It is difficult to determine if this as a result of treatment stopping or M.E. sufferer being unwell to attend hospital appointments as the questionnaire design did not allow for collation of such data.

- On the whole it appears a large percentage have received an appropriate level of treatment to allow them to address all issues. 39.7% of respondents dealt with all issues during treatment with 33.3% still receiving treatment.

DISCUSSION

The general overall view from responses of patients perception for length of time take to receive a diagnosis, time taken between diagnosis and treatment, perceptual experiences of treatment (in-patient/out-patient), chronicity and longevity it would appear, this illness for **all** M.E. sufferers has to varying degrees had an impact on the quality of life in the past and at the present time. The illness also appears to have previously exerted a very negative impact on the lives of more than 95% of the respondents.

The problem of negativity persists today as one of the primary consequences of this illness. In other words, many sufferers have learned to live with their condition an manage it as part of everyday life. However, residual effects are present in a significant percentage of those affected which is demonstrated by the responses recorded for questions 25, 26 27 and 31.

Most of the respondents complained there was an absence and or lack of information about this illness, particularly amongst health professionals (Questions 9, 14 and 20). Quite clearly, sufferers would appreciate if more health professionals were provided with additional information about this illness so as not to appear ‘ignorant’ or in some cases ‘arrogant’ when treating sufferers. This may also assist in promoting belief amongst health professionals this illness is a recognised medical physical illness with multi symptoms thereby regain the trust and respect of M.E. sufferers.

It would appear from the number of respondents who received a formal diagnosis from a GP (>35%) with a small number <2% being diagnosed by a psychiatrist (Table 2) that GPs have not been influenced by the Royal College Report issued to them by the Department of Health (DoH)**(1)** However, this cannot be confirmed at the time of completing this report as >96% had been diagnosed prior to the report being issued.

When we consider the volume of laboratory studies into vaccinations, antibiotics, antidepressant’s etc., which are all designated at some level as forming part of the immune system at some stage within the medical model. Accepting the view with the possible exceptions of ‘antibiotic’ and’ immunisation’ drugs, few improvements in health and wellbeing can be attributed to a break through within laboratory medicine, as few medical procedures are subjected to rigorous evaluation of their effectiveness**(2)**. Science and technological interventions often fail to address the more personal dimensions of suffering**(3)** which is certainly the case for M.E. sufferers.

Given recent claims and findings from traditional medical models who claim to have effective diagnostic tools, such as SPECT & PET**(4)** scans to measure somatic deficits in neurological disorders, is it possible to draw conclusions that visual and language deficits experienced by M.E. sufferers are neurological? If this was the case the same conclusions and arguments must be held for all other competing research disciplines. What is more concerning if SPECT or PET scans were viewed by the medical profession in general one would expect to see a higher percentage than 1.7% receiving these (Q12).

Table 10 reported a surprising finding from 8 respondents who reported there condition was improving until they undertook a graded exercise programme as recommended by the M.E. Specialist Team. Such findings only support the perception that each individual M.E. sufferer requires an individual care assessment plan which is regularly monitored and regulated to accommodate ones needs at any given time.

It is accepted the data collated from most of the questions set required to a large degree respondents to make a ‘perceived judgement’. In accordance with the NHS document ‘A Plan for all, a Plan for Change’, one of the major factors recorded as being primary to the planning and delivery of health care are the views and experiences of ‘service users’ (perceived judgements).

It is acknowledged that the small sample of respondents who took part in this survey does not represent the global population of M.E. sufferers.

SUMMATION

This illness has had a considerable impact on the life of each respondent, particularly with regard to lack of treatment, information, care management within the family and within the workplace.

Many of the respondents sought to take control and manage their symptoms and illness by trying a variety of alternative and complementary therapies, often at there own expense because conventional treatments, when offered had little or no effect and in some cases proved extremely detrimental. Should the NHS in the absence of conventional treatment being identified reimburse M.E. sufferers or should sufferers be able to re-claim all out-of-pocket expenses from the DSS. This is worth investigating.

There appears to be a real need for an independent epidemiological study of M.E. patients, that does not exclude sub-groups and which acknowledges assignment errors. This would be a step in the right direction rather than continue speculating and making assumptions that represent a specific target population. However, researchers need to be clear about what they understand and interpret from other's research, given the failure to observe information that is widely known, and have been demonstrated within a large volume of published research. Standardisation in research methodology and the ICD criteria would assist with these difficulties.

If practitioners and researchers do not work together, there is a danger that one day an effective diagnostic tool reported will be rejected or ignored, as was the case by medical practitioners when they failed to take into account pharmacological findings into the use of antibiotics(5).

Follow up investigations for medication, stress, depression and workplace environments as recommended by the findings from the August 2001 survey continues to be recommended in an attempt to collate qualitative data for 'high risk' occupations such as teaching, students and administration.

The data and statistics presented confirm the need for formal clinical standards to assist and provide health professionals with sufficient information and training to ensure effective early diagnosis and adequate health care planning by each Health Trust to ensure they meet the need of all M.E. sufferers.

APPENDIX 1

POST CODES FOR EACH REGION : QUESTION 22 - 24

SOUTH CENTRAL		
Post Code	Residence at illness onset	Residence today
GU (Guilford)	1	3
HP (Hemel Hempstead)	1	
OX (Oxford)	1	
PO (Portsmouth)	1	1
RG Reading)	1	1
SL (Slough)	1	3
SN (Swindon)	1	3
SO (Southampton)	2	1
TOTAL	**9**	**12**

SOUTH EAST		
Post Code	Residence at illness onset	Residence today
BN (Brighton)	1	4
CT (Canterbury)	2	2
DA (Dartford)	2	1
KT (Kingston-upon-Thames)	1	1
ME (Medway)	1	1
RH (Redhill))	2	3
TN (Tonbridge)	2	4
TW (Twickenham)	2	2
TOTAL	13	18

MIDLANDS		
Post Code	Residence at illness onset	Residence today
B (Birmingham)	8	4
CV (Canterbury)	1	1
DY (Dudley)		1
LE (Leicester)	4	3
NG (Nottingham)	4	5
NN (Northampton)	1	1
ST (Stockton-on-Trent)	3	3
WS (Walshall)	1	1
TOTAL	**22**	**19**

SCOTLAND		
Post Code	Residence at illness onset	Residence today
AB (Aberdeen)	1	1
DD (Dundee)	1	2
EH (Edinburgh)	6	6
G (Glasgow)	4	6
KA (Kilmarnock/Ayr)	1	1
KY (Kirkcaldy)	2	1
PA (Paisley)		1
PH (Perth)	2	1
TOTAL	**17**	**19**

SOUTH WEST		
Post Code	Residence at illness onset	Residence today
BA (Bath)	2	2
BH (Bournemouth)	4	3
BS (Bristol)	5	5
DT (Dorchester)	1	1
EX (Exeter)	3	4
GL (Gloucester)	4	3
HR (Hereford)	2	4
PL (Plymouth)	1	1
TA (Taunton)	2	3
TQ (Torquay)	1	
WR (Worcester)	1	2
DT (Dorchester)	1	1
TOTAL	**27**	**29**

NORTH WEST		
Post Code	Residence at illness onset	Residence today
CA (Carlisle)		1
CH (Chester)	2	2
L (Liverpool)	2	2
LA (Lancaster)	1	
M (Manchester)	3	3
PR (Preston)	1	2
TOTAL	**9**	**10**

Appendix 1 continued

NORTH EAST		
Post Code	Residence at illness onset	Residence today
BD (Bradford)	1	
DH (Durham)	1	
DN (Doncaster)	3	2
DL (Darlington)	1	1
HG (Harrogate)	2	2
HX (Halifax)	2	1
LS (Leeds)	3	2
NE (Newcastle Upon Tynes)	3	5
S (Sheffield)	2	2
YO (York)	1	1
TOTAL	**19**	**16**

ANGLIA		
Post Code	Residence at illness onset	Residence today
CB (Cambridge)		1
CM (Chelmsford)	1	
CO (Colchester)	2	2
EN (Enfield)	1	
LU (Luton)	2	2
NR (Norwich)	4	5
PE (Peterborough)	2	4
RM (Romford)	1	
SG (Stevenage)	2	2
SS (Southend-on-Trent)		2
TOTAL	**15**	**18**

LONDON		
Post Code	Residence at illness onset	Residence today
E (London E)	2	
N (London N)	5	1
NW (London	5	2
SE (London SE)	4	2
SW (London SW)	2	1
W (London (W)	2	2
TOTAL	**20**	**8**

THOSE LISTED ABROAD		
Post Code	Residence at illness onset	Residence today
GY (Guernsey)	1	1
Holland		1
USA	1	1
South Africa	1	
Australia	1	
TOTAL	**4**	**3**

NORTHERN IRELAND		
Post Code	Residence at illness onset	Residence today
BT		1
Eire		1
BJ (Ballycastle)	1	1
DH Co-Durham		1
TOTAL	**1**	**4**

WALES		
Post Code	Residence at illness onset	Residence today
LL (Llandudno)	2	3
NP (Newport)	1	2
SA (Swansea)	1	
CF (Cardiff)	1	1
SW (Abersystwyth)	1	
TOTAL	**6**	**6**