

Clinical Assessment, Management and Outcomes of a Group of Adolescents Presenting with Complex Medico-psychosocial Conditions

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Abstract

Background: Adolescents with complex medico-psychosocial presentations are often seen as a management challenge. The Medical Family Therapy model provides a useful framework for working with these patients in the context of a multidisciplinary approach to treatment. **Materials and Methods:** A retrospective case analysis of 38 patients referred over a two-year period to the Department of Adolescent Medicine was carried out. These patients met DSMIV criteria for somatoform disorder or had a diagnosis of chronic fatigue syndrome (CFS). Duration of symptomatology, diagnosis, the presence of psychiatric conditions in the young person and their immediate family and the type and duration of the intervention were examined in relation to outcome. Two case presentations illustrate the complexity of the assessment and treatment process. **Results:** Clinicians rated 47% of patients who engaged with the service as improved. There was no relationship between diagnosis, length of intervention and outcome. No significant differences emerged between the group of young people diagnosed with CFS and those with somatoform disorders in terms of outcome. Nine patients presented with symptoms which were similar or identical to those of one of their parents. Physical illness was more likely to be reported as a precipitating factor in the CFS group. Poor school attendance and psychiatric morbidity were linked to poor outcome. **Conclusions:** A comprehensive evaluation of presenting symptomatology and focussed intervention with measurable outcomes are important aspects of the clinical approach to complex medico-psychosocial conditions in adolescents. Families' beliefs about the presenting symptomatology and experiences of illness should be explored.

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Key words: Chronic fatigue syndrome, Medical family therapy, Somatoform disorders

Background

Increased sensitivity to biological change can make adolescents particularly vulnerable to non-organic symptomatic disorders.¹ A variety of pains, headaches, dizziness and fatigue may remain unexplained after medical assessment.² Such cases are often referred to as the functional syndromes of chronic fatigue, chronic pain, fibromyalgia and irritable bowel syndrome or as somatoform disorders. In many cases, the symptoms are severe and disabling, but may have been dismissed as insignificant or attributed to mental illness.³ The aetiology of many of these conditions remains unknown and the underlying disease process cannot currently be defined. As new knowledge emerges, disease categories are changed and refined.⁴ The suffering

and disability which many of the young people experience are considerable, exacerbated by uncertainty around diagnosis and 'invisible' illness out of proportion to symptoms. They all experience disruption of school and peer relationships, as well as additional stresses in family relationships. However, the labelling of these patients on the basis of presenting symptoms may convey little about their underlying difficulties.⁵

Adolescents with these types of presentations are often seen as a management challenge, undergoing numerous medical investigations without an organic explanation for their symptoms being obtained. However, despite the evidence of elevated rates of psychiatric symptoms and family problems in such cases, there is often reluctance to

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address psychological or relationship issues.⁶ These young people and their families usually consider their difficulties very much in physical terms and therefore much more readily accept consultation from a physician than a psychiatrist.⁷ It is the young people with symptoms of a significant enough duration and complexity who come to the attention of tertiary services. The advantages of adolescent medicine involvement include thorough medical work up or review and the limiting of further unnecessary investigation. The physician contact is not contingent on an escalating sick role⁸ and helps to contain the patient and their family.

One of the earliest conceptualisations of these types of patients was that of Pilowski (1969). He used the term “abnormal illness behaviour” to describe the presence of physical symptoms which were over-valued, out of proportion to the demonstrable somatic pathology and of sufficient duration or severity to cause concern.⁶ Although this concept stimulated debate, it is not one that can be easily shared with families. As well as having negative connotations, it may be seen as diminishing the medical symptoms, which for many of the young people and their parents are paramount. The terms “chronic fatigue syndrome (CFS)” and “somatoform disorder” avoid this pejorative labelling. However, Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) criteria for the latter have been criticised as being too restrictive for use in adolescents, most of whom end up in the ‘undifferentiated’ category.

The importance of involving the family in the resolution of these problems needs to be recognised both in terms of exploring the meaning and function of the symptoms, but also helping the family develop positive coping strategies. Although families are thought to play a role in chronic pain and its consequences, the mechanism of transmission of these problems remains unknown.⁹

Families with severely somatizing members often develop ways of interacting that seek to avoid any emotional pain.¹⁰ If these coping mechanisms are challenged before the family engages with the service, they may drop out prematurely. The Medical Family Therapy model¹⁰ provides a useful framework for working with these families. This model assumes that no biomedical event occurs without psychosocial repercussions, and that no psychosocial event occurs without some biological features. It aims, through a collaborative approach with the family, to create therapeutic stories that are mutually acceptable to the patient, the family, the therapist and the doctor. It moves away from the process by which the medical and psychological can become polarised and families are told that symptoms they perceive as medical are in fact emotional or psychological. This “Either–Or” process often leads to power struggles with professionals. The aim here is to move towards “Both–

And” thinking,¹¹ eventually allowing for the link to be drawn between somatic and psychological factors. The goal may not be the ‘cure’ of the illness but the acceptance of medical uncertainty about the source of the symptoms, decreased expectations for a cure, less conflict with doctors and a limit on exploratory tests as well as increased pleasure in life. The aim is to promote the young person’s and family’s effectiveness in managing the illness and other aspects of their lives. The Medical Family Therapy model also allows for the inclusion of a range of other therapeutic interventions, for example, relaxation techniques, which have been found to be helpful in treating headaches, conversion disorder and pain syndromes.¹² It can also fit comfortably within a rehabilitation process for young people with CFS.

Empirical data on treatment efficacy are limited for somatizing children and adolescents as well as for adolescents with CFS.^{7,13} Family cognitive-behaviour therapy for recurrent abdominal pain has demonstrated better outcomes and lower rates of relapse at up to 12 months’ follow-up than usual paediatric treatment without psychological intervention.¹⁴ A recent review of the effectiveness of intervention used in the treatment of chronic fatigue in adults and children found promising results for cognitive behaviour therapy and graded exercise in adults.¹⁵ An intensive inpatient rehabilitation programme for adolescents with CFS is effective in the treatment of many young people although it is not a treatment that appeals to all families.¹⁶ Other studies have found no clear relationships between treatment and outcome but parents reported that the attitude of the treating doctor was found to be important in a good outcome, including acknowledging the family’s concerns about physical illness and setting realistic treatment goals.¹⁷

Setting for the Study—The Adolescent Medical Unit

The Adolescent Medical Unit, the clinical service of the Department of Adolescent Medicine at The Children’s Hospital at Westmead, provides health care for young people in the age range 12 to 18 years presenting with medical, health and developmental concerns. As a secondary/tertiary facility, there is a predominance of problems at the more severe and complex end of the spectrum. A comprehensive multidisciplinary approach is taken with all referrals to the general clinic where the young people with complex medico-psychosocial presentations are referred. Initial assessment is undertaken jointly by an adolescent physician and a social worker or psychologist. A plan of intervention is formulated with the young person and their family combining medical monitoring, individual counselling and family support or therapy. A range of individual and family based

interventions is offered. Other medical subspecialty or psychiatric opinions may be sought. The team's occupational therapist is often consulted for relaxation training, review of activities for daily living or graded return to school. Liaison with school is an important role of the allied health clinic staff. There are also close links with the adolescent ward to which young people may be admitted for rehabilitation or further investigations if necessary.

The Department offers a multi-disciplinary rehabilitation programme for young people with chronic fatigue. The programme involves medical, physiotherapy, occupational therapy and nutritional assessment and management. There is also psychosocial input which may include both individual and family therapy and psychometric assessment. The overall aim is to provide a coordinated programme, which may begin with a period of inpatient care followed by regular outpatient review (Fig. 1).

The aims of the research were:

- 1) To determine if individual or family variables can be used as indicators of good or poor outcomes;
- 2) To establish whether the interventions offered were effective and develop more rigorous ways of measuring outcome for this group of young people.

Materials and Method

A retrospective case audit was conducted on 38 patients referred over a two-year period (1999 to 2000) to the Department of Adolescent Medicine. These patients met DSM-IV criteria for somatoform disorder or had a diagnosis of CFS.¹⁸ A range of variables was explored in relation to outcome, including the duration of symptomatology and other developmental and health concerns, diagnosis, the association of psychiatric conditions in the young persons and their immediate family, the physical health of the parents and the type and duration of the intervention. Clinical outcome was established by reading the notes and through discussion with the treating physician. Families were also contacted by telephone by a member of the psychosocial team and asked their views on the young person's problems and the help received in the Department. Two case presentations are used to illustrate the complexity

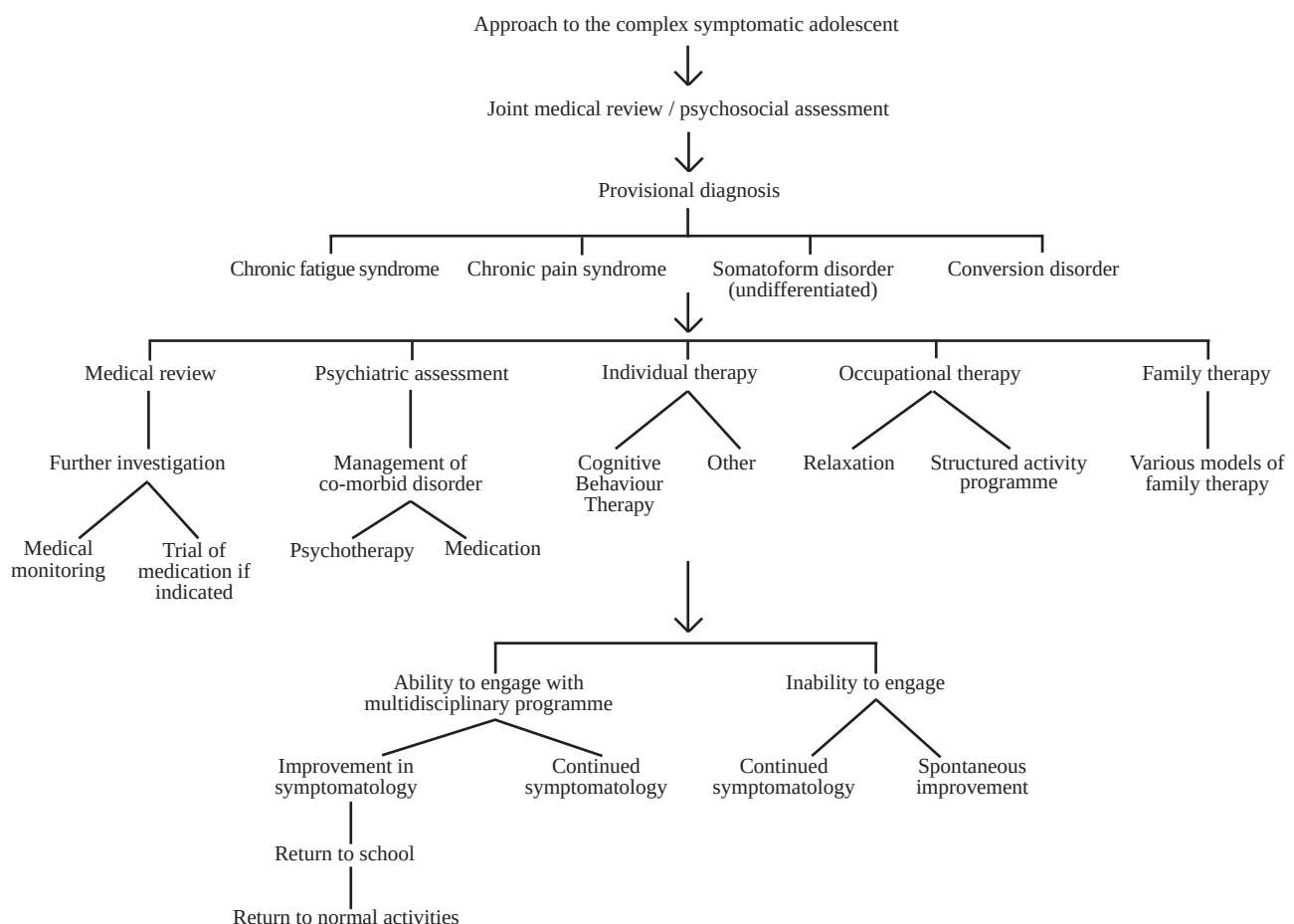


Fig. 1. Approach to the complex symptomatic adolescent.

TABLE I: DEMOGRAPHICS AND DIAGNOSIS

	n	%
Age (at referral)		
Early adolescence (12-13 years)	14	36.8
Middle adolescence (14-16 years)	24	63.2
Gender – Female	33	82.5
Adolescent born in Australia	36	95
Living with both parents	31	81.6
Diagnosis		
Chronic fatigue syndrome	13	34
Conversion disorder	2	66
Pain disorder	13	
Undifferentiated somatoform disorder	10	
Source of referral		
General practitioner	26 (68.4%)	
Paediatrician	5 (13.2%)	
Inpatient/Emergency Department	5 (13.2%)	

of the assessment and treatment process. The results were analysed using chi square and non-parametric correlations because of the small sample size and lack of normal distribution of the data.

Results

A large proportion of the young people were Australian-born and lived with both parents. Thirteen (34%) of the sample had a diagnosis of CFS and 66% of somatoform disorder. The majority had been referred to the service by their family doctor (68.4%), although 13.2% had come directly from the Emergency Department or inpatient ward (Table I).

Presenting Problems

Seven of the sample had developmental problems, which included early concerns about motor or language development, and prematurity, although none of the group was identified as having current learning disability or special needs. This was not related to outcome (Fisher's exact, $P = 0.344$). A number of the young people also had other physical problems such as asthma, but the presence of these was not related to outcome (Fisher's exact, $P = 0.456$). However, the presence of depression ($n = 4$, 10.8%) or anxiety ($n = 7$, 18.4%) was associated with poor outcome ($\chi^2 = 3.656$, $P = 0.056$).

Young people in families who did not clearly identify a precipitating reason for their symptoms had better outcomes than those who did ($\chi^2 = 4.57$, $P = 0.033$). A greater proportion (36% versus 8%) of young people presenting with somatoform disorders than chronic fatigue identified family or school-based stress as precipitating their symptoms. Conversely, a greater proportion of young people with chronic fatigue identified physical illness as

TABLE II: OUTCOMES

	Total n (%)	CF n (%)	SD n (%)
Clinician rated – problem improved or resolved	18 (47.4%)	4 (30.8%)	14 (56.0%)
Family rated – problem resolved or improved	14 (82.0%)	5 (85.7%)	9 (81.8%)
Did not attend	1 (2.6%)	1 (7.7%)	0 (0.0%)
No. of appointments			
Range	1-40	1-24	1-40
One appointment only	18.4%	7.7%	24%
2-10 appointments	44.1%	15.4%	83.3%
Length of input (months)			
Range	1-46	1-46	1-24
Mean	8.5	13.08	8
Inpatient treatment	11 (28.9%)	4 (30.8%)	7 (28.0%)

CF: chronic fatigue; SD: somatoform disorders

precipitating their symptoms (31% versus 16%). However, since the numbers were small, no statistical analysis was undertaken.

School attendance was impaired in the majority of cases, with only 6 (16%) of the young people attending regularly. Seventeen (44.7%) had frequent days off while 11 (29%) were not attending at all during the period of treatment and monitoring. The duration of problems at presentation ranged from 1 to 96 months (mean 18.3 months) with little difference between the CFS (mean 19.6 months) and somatoform (mean 17.76 months) groups. There was no correlation between duration of symptoms and outcome, which depends more upon the ability of the team to engage with the young person and the family around the illness.

Family's Mental and Physical Health Problems

Nine of the young people presented with very similar or identical physical complaints to those experienced by their parents including chronic fatigue, headaches and abdominal pain. However, this did not appear to be a poor prognostic sign in itself. The presence of physical health concerns in the parents did not appear to be associated with outcome ($\chi^2 = 0.27$, $P = 0.870$), although young people with CFS were more likely than those with a somatoform disorder to have a parent with a physical health problem ($\chi^2 = 4.937$, $P = 0.026$). The presence of mental health problems in the mother was not associated with outcome (Fisher's exact, $P = 1.0$). No fathers reported mental health problems.

According to the physician rating, the symptoms of nearly half of the sample improved or resolved. If those patients who did not attend or for whom outcomes were unknown were excluded from the analysis, the improvement

rate was higher (56%). There was no statistically significant difference in clinician-rated outcome for the two groups ($\chi^2 = 2.694$, $P = 0.101$). In total, 19 (53%) families gave their feedback. The majority (84%) reported that the symptoms that had brought them to the Department had got better or completely resolved. For two young people the symptoms had remained the same (11%) and one adolescent could not recollect why she had attended the Department. There was a 67% consensus between the parent/young person's and clinician's rating, with families reporting more positive outcomes (Table II).

Of the 5 families who reported that they had not found the intervention helpful, 3 had specific criticisms. One had found a psychiatrist's insistence that she take medication unhelpful and felt she had not been heard. One complained about being directed back to her referring doctor whom the patient did not like. One felt some of the medical professionals' attitudes detrimental to her daughter's condition. Forty-two per cent of the young people continued to have some concerns about their health and were currently involved with services because of these concerns. Despite this, all but two (11%) young people were in work or school and only three were in part-time placements as part of rehabilitation.

There was no significant relationship between inpatient treatment and outcome ($\chi^2 = 0.008$, $P = 0.930$). The young people with CFS tended to be seen over a longer time period, with the majority having over 10 appointments with various members of the multi-disciplinary team. Only 16.7% of the young people with somatoform disorders were seen for over 10 appointments. There was, however, no significant correlation between length of problem duration and length of input from the service (Spearman's $r = 0.146$).

Where a co-morbid mental diagnosis was suspected at presentation, the Department's psychiatrist was consulted, leading to use of medication in some cases. It is not known whether or not this affected the outcome due to concurrent interventions including medical review, individual support and family therapy. The complexity of the cases is illustrated through two case examples, the first with a good outcome and the second with an unresolved outcome.

Case One

Lucy Jones, aged 14 years, first attended the Emergency Department because of light-headedness, with tingling of hands and feet and an episode of fainting. With a strong familial history of prolonged QT syndrome, she was admitted for Holter monitoring which revealed episodes of prolonged QTc (up to 0.56 msec). Her Atenolol was increased from 25 mg daily to 25 mg bd. Five months later, Lucy returned to the Emergency Department because of

headaches. While these had been recurrent for the previous 12 months, they had increased in severity in recent days and were associated with nausea and vomiting, paraesthesia of hands and feet and lethargy. There was a strong family history of migraine on her father's side. Physical examination including neurologic exam and CT scan were normal. A review of the psychosocial history prompted referral to the Adolescent Medicine Department.

Lucy lived with her father and two sisters. Mrs Jones, her mother, who had been on Prozac for the past 9 years, had QT syndrome and was also on thyroxine for hypothyroidism. She had left the family in the preceding year but continued to see the children on a regular basis. The family experienced a number of other stressful life events over the preceding four years. The family business went bankrupt, they were faced with significant financial hardship and had to move interstate when Mr Jones found a new job. Lucy had a difficult relationship with her mother and reportedly found contact quite stressful. For the previous 6 to 8 months, she and her 2 sisters had been seeing a social worker.

Lucy was reported to be doing well academically, although her schoolwork suffered because of headaches and emotional difficulties leading to absences from school. She denied any form of bullying, had good peer relationships, denied using drugs, alcohol or cigarettes and had no sexual concerns or suicidal thoughts. However, she reported having sleep difficulty and was concerned about being overweight. She avoided any form of exercise because of her heart condition.

Gentle exploration of the psychosocial and family issues and a thorough medical review were undertaken. Lucy was assessed as having chronic headache, prolonged QT syndrome, depression and obesity [102 kg (>97%) with BMI of 34.7]. The family were open to exploring both the medical and psychosocial aspects of Lucy's difficulties and engaged well with the service. Family therapy focussed on the relationship difficulties between Mr and Mrs Jones and the children's relationship with their mother. Lucy was commenced on Sertraline 50 mg daily and was seen individually for Cognitive Behaviour Therapy and relaxation, while the Adolescent Physician continued to monitor symptoms and progress. On discharge from care, Lucy's headaches and other physical symptoms had improved. She was attending school full-time and doing well in her studies. Her sleeping had also improved. Relationships in the family were being managed in a much more constructive way. This family had been able to accept the relevance and importance of addressing the psychosocial issues.

Case Two

The Emergency Department referred Angela, aged 13, to

Adolescent Medicine because of recurrent presentations with disabling abdominal pain. Cholecystectomy for gallstones had been performed 3 years previously and recurrent RUQ pain had developed in the weeks following surgery. She was reviewed and reassured by her surgeon and subsequently referred to the Pain Clinic for further assessment and advice regarding management. As part of the Pain Team assessment, review by a Child and Adolescent Psychiatrist was arranged. Angela and her mother felt this was unnecessary and unhelpful and, after not returning for follow-up, was managed by her GP who used increasing amounts of analgesia. Angela had in fact not returned to full-time school since her surgery. She and her mother had also sought opinions from other medical specialists regarding diagnosis and management of her pain.

On initial presentation to Adolescent Medicine, Angela was found to have marked RUQ tenderness. She complained also of persistent nausea, fatigue and inability to concentrate. Medical review was undertaken with liaison with her GP and other involved specialists. Psychosocial assessment revealed a household of mother and daughter, both estranged from other family support and with few friends. The mother was receiving a carer's pension and both she and her daughter were fixed on attaining a definitive diagnosis and treatment of her pain.

With intensive individual and family support, and liaison with the school, Angela gradually increased her attendance at school and was meeting her academic goals. Over the summer holidays (three months) her symptoms increased, however, and she did not return to school in the new year. Distance education was arranged. During an inpatient rehabilitation admission to hospital, good results were achieved with Angela's participation in a full programme of morning school, creative arts group activity each afternoon, physiotherapy and hydrotherapy, timetabling and organisation of a daily schedule of graded activity. This programme was sustained for some weeks when back home again with regular monitoring by the team (weekly, to second-weekly). However, Angela again deteriorated with an escalation of her symptoms.

There were concerns about the enmeshed mother-daughter relationship, absence of social and peer interaction, and the possibility of more serious psychiatric and child protection aspects. Angela and her mother were therefore referred to an Adolescent Psychiatric hospital for a more prolonged residential rehabilitation programme and re-integration into her normal school. Several meetings were held to ensure this transition was successful, as both Angela and her mother were distrustful and distressed at their perceived abandonment. There were telephone conferences between the GP, medical specialists, Adolescent Psychiatry team and Adolescent Medicine. It

was agreed that the Adolescent Medicine team would maintain a role of back-up medical monitoring and support for Angela and her mother as needed while they participated in the Adolescent Psychiatry programme.

Despite all efforts, Angela and her mother were unable to tolerate the separation required for her to remain in the hospital. She continues to be in contact with the Psychiatry team but minimal progress has been made. In this case, with an unresolved outcome reflecting more significant psychopathology, there had been little success in shifting the family's health belief model.

Discussion

Notwithstanding the small sample examined, the study confirms the benefits of a multi-disciplinary approach to the treatment of medico-psychosocial disorders. The most favourable outcomes were seen in those young people and their families who were able to engage with the service and address both the medical and psychosocial aspects of their presentation.

The high prevalence of girls in the sample reflects the higher prevalence rates of both CFS and somatoform disorders in females.^{19,20} There were proportionally fewer young people born overseas than may have been expected in the locality. This may reflect the referral patterns of paediatricians and general practitioners, as well as the models of physical health held by different cultural groups. The sample closely reflected the family structure of the general Australian population.

A recent survey of the mental health of young people in Australia indicates that 15% to 20% of children and adolescents have a psychiatric disorder, although only a quarter of these will seek help.²¹ The rate of depression is reported to be 5%, as compared with 10.5% of our study sample, which corresponds with elevated rates reported in other studies.^{4,22} The rate of anxiety is also higher than in community studies while the rate of deliberate self harm in this sample (5.3%) appears similar to the rates of serious suicidal ideation reported by GPs in those under the age of 25 (5.7%).²³

A relationship between poorer treatment outcomes and maternal psychopathology and handicapping chronic health problems has been suggested in children with CFS.¹⁷ The elevated rate of chronic illnesses and chronic fatigue in other family members is also noted in the literature.^{24,25} No association was found in this study between maternal mental health and outcome. However, in order to get more accurate results of prevalence, parents should have been asked to rate their own mental health status. The high incidence of physical complaints in the parents and children is of interest, suggesting exposure to influences in the environment or genetic vulnerabilities. Ongoing health

problems in a child can also result in additional stress on the family. The presence of a persistent health problem provides the opportunity for modelling of appropriate coping behaviour by parents which can help the adolescent deal more effectively with their own difficulties. Alternatively, there may be a family belief that certain predicaments can only be resolved through illness behaviour and the young person's difficulties may be reinforced and perpetuated by their parents' response.²⁶

In addition to the small sample size, we recognise other limitations of the study, including the lack of a comparison group and the fact that the raters of outcome were not blinded. However, the case review was undertaken as a precursor to a more extensive evaluation study of patients presenting with complex medico-psychosocial conditions and raises a number of important questions in relation to approaching the assessment and management of these challenging young people.

Conclusion

In approaching complex medico-psychosocial presentations in young people, outcome measures are useful in the clinical context, as well as providing objective markers of improvement. We recognise the need to look at outcomes more systematically in this group of young people. The current study points to the importance of specifically assessing both the mental and physical health of the young persons and their immediate family. There is also a need to examine beliefs about the cause of their symptoms. Those who clearly identify physical precipitants for their symptoms and have a strongly held belief in physical aetiology, and a family history of similar symptoms, may be most difficult to engage and achieve positive outcomes.

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