Tidsskriftet Tidsskrift for Den norske legeforening

A young boy with unexplained headache and paralysis

EDUCATIONAL CASE REPORT

SOLVEIG GJEMS

Department of Child and Adolescent Mental Health in Hospitals
Division of Paediatric and Adolescent Medicine
Oslo University Hospital, Rikshospitalet
Solveig Gjems is a specialist in clinical child and adolescent psychology.
The author has completed the ICMJE form and reports no conflicts of interest.

HELENE HELGELAND

E-mail: helene.helgeland@ous-hf.no
Department of Child and Adolescent Mental Health in Hospitals
Division of Paediatric and Adolescent Medicine
and
National Advisory Unit on Psychosomatic Disorders in Children and Adolescents
Oslo University Hospital, Rikshospitalet
Helene Helgeland, PhD, is a specialist in child and adolescent psychiatry.
The author has completed the ICMJE form and reports no conflicts of interest.

A young boy of upper primary school age was admitted to a paediatric ward with headache, paralysis and reduced general condition. A thorough physical examination was necessary and informative. However, the biomedical approach provided incomplete understanding of the boy's symptoms, leading to a delay in initiating effective treatment.

A previously healthy, physically active and well-functioning boy was admitted to the paediatric ward with reduced general condition, headache and muscle weakness in his arms and legs. Two weeks prior to his admission, he had experienced rapid-onset headache, low-grade fever, reduced appetite and a few days of transient stomach pains. Prior to that, he had felt unwell and had experienced recurrent headache for 3–4 months. His general practitioner had prescribed 10 days of Apocillin early in the disease course owing to pharyngeal rubor, but there were no other clear signs of infection and his weight was stable. There was nothing in his medical history to suggest a tick bite.

The results of a comprehensive physical examination were normal with the exception of reduced power and weak deep tendon reflexes in the upper and lower extremities, and somewhat fluctuating tonus upon testing of muscle power. Other neurological tests yielded normal results. Additional tests including blood tests, among them haematological-, liver-, kidney- and infection parameters (including borrelia IgG and IgM antibodies) and hormones were all normal. Chest X-ray, abdominal ultrasound, MRI of the brain and medulla, standard EEG and neurography were normal, as were the results of cerebrospinal fluid analysis. The lumbar puncture was uncomplicated, but immediately after the procedure the patient's strength in his lower extremities deteriorated markedly. He ceased walking completely and from this point onwards used a wheelchair to move around. He felt dizzy and unwell whenever he attempted to use his legs. A physiotherapist observed that the boy had poor gait when using a walking frame, but that his movement pattern was otherwise normal.

The paediatricians concluded that the boy's symptoms could not be explained by any known somatic disease, and a functional disorder was suspected.

Functional disorders refer to bodily symptoms for which medical assessment fails to reveal any known physical explanation (1). Examples may include chronic pain, paralysis, seizures, fatigue, or combinations of these. Not infrequently, an infection or physical injury, a known comorbid disease, or a medical procedure or surgery may be a triggering factor (2). This stands in contrast to the common perception that functional disorders are due only to psychological factors.

While the tests were ongoing, the family felt that they were well supported by the hospital. However, when the physical examinations failed to reveal an explanation for the boy's symptoms, they felt that they were left to cope on their own. The family felt that they were not informed as to why the boy had stopped walking following the lumbar puncture and whether the paralysis might be permanent. They had the impression that healthcare personnel trivialised the symptoms by implying that there was actually nothing wrong with the patient and that there were no physical reasons for the paralysis. At the same time, other serious diagnoses were proposed (e.g. chronic fatigue syndrome, CFS/ME), without the patient and his parents feeling that efforts had been made to justify or explain these diagnoses further.

The boy was discharged in a wheelchair with persistent weakness in his legs, headache and fatigue. The physiotherapist referred him for follow-up with the municipal physiotherapist, and an outpatient appointment was arranged

with the paediatrician for approximately two months' time. Nonetheless, shortly after discharge, the boy was assessed several times at the paediatric outpatient clinic owing to persistent symptoms that caused great anxiety in his parents. The findings were consistent with those of previous physical examinations. He was encouraged to resume normal activity and to return to school. He was also referred to another hospital for assessment for suspected chronic fatigue syndrome and received an appointment in 10 weeks' time. In addition, he was referred to the child and adolescent mental healthcare service.

In our experience, when a patient's symptoms cannot be explained by a demonstrable disease, many paediatricians conclude that the symptoms are psychiatric in origin and therefore beyond the scope of their expertise and responsibility. We find that patients are often discharged from hospital without an adequate explanation for their symptoms and without any offer of support beyond sporadic outpatient follow-up by a paediatrician or general practitioner. Some are referred for follow-up by the mental healthcare services without the family understanding why. Many patients and families feel distrusted and dismissed (3, 4).

The suggestion that the patient might have chronic fatigue syndrome led to increased concern in the family. The parents feared that their son's condition would deteriorate if he attended school or otherwise exerted himself. They were also worried about whether the lumbar puncture had caused the paralysis and whether the damage might be permanent. Their questions remained unanswered, probably due to inadequate communication between the parents and doctors. The parents were open to their son being referred to the outpatient child and adolescent psychiatric clinic, but doubted whether this was appropriate for him. They regarded his symptoms as physical in nature.

In the interim, the family attended a number of appointments with their general practitioner, who was available and supportive but wished to await the results of assessment by the second-line services. The boy received follow-up from the municipal physiotherapist, but both the physiotherapist and the boy's parents were unsure how much he should move or practice walking. They were afraid that his condition could deteriorate, and the parents therefore sought advice from the hospital paediatrician. They were told that he could undergo training in walking and attend school, possibly with shortened school days, but were not given more specific instructions. The parents came to an agreement with the school that he should attend for an hour a day three days a week. His headache increased upon any exertion, however, and his planned school attendance was inconsistent. He managed little in the way of physiotherapy or socialising with friends and spent many hours in front of screens (TV, computer games). At home, he moved around by crawling and when outside, he used a wheelchair. There was no sign of any improvement, instead his condition gradually deteriorated. This caused growing concern in the family.

Follow-up was initiated at the local outpatient child and adolescent psychiatric clinic, six sessions in total. These consisted mainly of taking the medical history, profiling psychosocial factors, and counselling. The conclusion was that he did not fulfil the criteria for a psychiatric diagnosis.

Since he had functioned well socially prior to the event in question and there were no obvious familial tensions, the psychiatrist concluded that there was most likely a physical basis for the condition. The psychiatrist offered further counselling sessions, but the family nevertheless felt powerless. They felt that medical professionals differed in their interpretation of the boy's symptoms and offered conflicting and unclear advice.
When the boy was finally assessed as an outpatient by a paediatric neurologist at another hospital, chronic fatigue syndrome was ruled out. His symptoms continued to be regarded as functional. He was referred for interdisciplinary assessment at the same hospital and was admitted ten months after symptom onset.
Since he had been thoroughly assessed at the local hospital, there was no indication for further physical assessment beyond a new neurological examination and blood tests. All yielded normal results. A thorough child psychiatric, cognitive and physiotherapeutic assessment was performed. The interdisciplinary team concluded that the patient fulfilled the criteria for the diagnoses dissociative motor disorder and persistent pain somatoform disorder.

In persistent somatoform and dissociative disorders, the child's vulnerability to and exposure to stress are expressed as persistent bodily symptoms (1). The stressors concerned may be physical (illness, injury, infections) or emotional, or they may be stressful life events. Such conditions reveal that the patient's capacity to cope has been exceeded. They often reflect the cumulative effects of multiple minor stressors (5). In dissociative motor disorder, muscles and movement are affected, with the symptoms unexplained by any known demonstrable injury or disease, and the patient unable to control them.

In conversation with the family it emerged that both mother and child were highly sensitive and anxious regarding bodily symptoms. The family viewed the boy's symptoms, the circumstances surrounding his admission and the lumbar puncture itself as distressing. In the same period, the family also had to deal with serious illness in another close relative. In our view, the situation as a whole led to an unmanageable emotional overload for the boy, which in turn contributed to the emergence of his paralysis. Gradually, other factors contributed to sustain and exacerbate the condition. Persistent anxiety and uncertainty in the family, the parents' attentiveness to the boy's symptoms and efforts to protect him by offering assistance, as well as inadequate knowledge and handling of the situation by the healthcare system, were all considered to be sustaining factors by the interdisciplinary team.
The goal of interdisciplinary assessment is to obtain a comprehensive, biopsychosocial understanding of the symptoms together with the patient and his/her parents. By identifying key sustaining factors, a treatment plan can be developed for further care.

The biopsychosocial model provides an appropriate framework for understanding and treating this type of disorder (6). According to the model, illness and symptoms can be understood as the result of a dynamic interplay between biological, psychological and social factors that can predispose to,

trigger and sustain a patient's symptoms. In such a dynamic model other factors and mechanisms can contribute to persistence of symptoms than those initially triggering them (6).

This patient population requires comprehensive, multimodal and individualised treatment (5, 7). The treatment may involve combining interventions at the child's school, at home and in the child's free-time, with physiotherapy, psychological/family therapy and/or medical treatment.

A collaborative working group was established in which the boy's parents and school, as well as the outpatient child and adolescent psychiatric clinic, pedagogical-psychological service and physiotherapy service were all represented. The boy's general practitioner would ideally also have participated in the meetings to provide a medical perspective, but was unable to attend. However, the general practitioner was well-informed about the patient and was available if required.
The boy had good learning potential, but required individualised schooling. A plan was made to gradually increase the amount of time he spent at school and to tailor the academic content of schoolwork. Instead of having to catch up on the work he had missed, he was given tailored support to return to schoolwork and activities. To reduce the demands and pressures of schoolwork, he required exemption from homework and tests for a period of time.
The boy received weekly follow-up from the municipal physiotherapist. Over time, he had become afraid of and resistant to using his legs. The physiotherapist avoided walking exercises in order to reduce the boy's focus on his symptoms and thereby avoid exacerbating them. Instead, the focus was on play-based activities centred around the boy's interests and functional level. He gradually became confident that he could use his body without his condition deteriorating.
The patient required follow-up at the outpatient child and adolescent psychiatric clinic, but not in the form of individual therapy. After the long period of illness, it was more important to help him resume normal everyday activities and to strengthen his identity as a healthy individual. This was also communicated to the parents in dedicated counselling sessions at the outpatient clinic. They also received help to manage their own anxieties, to tone down their focus on symptoms and to resume a normal family life.
Three weeks after the interdisciplinary assessment and rapid initiation of local interdisciplinary follow-up, the boy started walking again. Over subsequent months, he gradually resumed participation in school and activities. He continued to improve, and after a further ten months he was symptom-free and fully back at school and participating in activities.

Discussion

The medical history demonstrates how predisposing factors in the child in combination with various stressors triggered a complex clinical picture. In the following, we will focus in particular on how what we consider to represent

inadequate knowledge and handling of the situation by the healthcare system contributed to deterioration and an extended disease course.

There appears to be a widespread misunderstanding, both among medical professionals and in the general population, that the absence of a demonstrable physical disease means that symptoms must be purely 'psychological' and therefore not real bodily ailments. The biomedical model of disease that draws a sharp distinction between physical and mental illness is unsuitable for the management of patients with apparently inexplicable physical symptoms. Today, we know that such symptoms are the result of an interplay between biological, psychological and social factors (1, 4, 7).

It is currently unclear who bears responsibility for the follow-up of young patients with 'unexplained' physical symptoms. Many patients are referred back and forth between different specialists with no consideration of the overall picture. This contributes to a fragmented and inadequate understanding of the child's condition and increases the risk of unnecessary assessments and ineffective interventions. This is unfortunate as we know that early diagnosis and treatment improves prognosis and prevents a lengthy and disabling disease course (7).

An effective medical assessment is not just about detecting or excluding somatic disease. When somatic illness has been ruled out, the family must be given a meaningful explanation for their child's symptoms. In the mental healthcare services too, this patient population often receives insufficient understanding and follow-up. It is our impression that many patients are dismissed if they do not fulfil the criteria for a psychiatric diagnosis, and that medical professionals often are unsure of how symptoms should be understood when the child has neither obvious psychiatric symptoms nor any known physical basis for their condition. The manner in which healthcare professionals communicate with patients and their relatives has proven crucial for the course of unexplained physical symptoms (8). To dismiss, trivialise or signal that the child's symptoms are not real can be experienced as deeply offensive and can be a strong sustaining factor.

Treatment of this patient group requires interdisciplinary collaboration between the somatic and mental healthcare services, schools and other involved parties. A shared understanding of the condition and a consensus on follow-up are essential for success. Interdisciplinary management should mean that the professionals involved engage in mutual dialogue and collaboration, not simply exchange information in written referrals. Our impression is that the current healthcare system has neither experience with nor prioritises interdisciplinary collaboration with respect to this patient group. Possible explanations may include insufficient knowledge, lack of psychiatric expertise in paediatric wards, lack of willingness to accept responsibility for this patient group, time pressures and poor financial support.

It is also our impression that the specialist healthcare service focuses too much on the testing and diagnosis of this patient group, and to a lesser degree on treatment. This is left to the general practitioner, who is often unable to manage the care of these patients alone. Schools too may also not receive

sufficient support from the healthcare profession, in following up children and adolescents who are unable to attend. In this way, the healthcare service contributes to poor recovery.

In our experience, patients with functional disorders should be treated in both the primary and secondary healthcare services. An interdisciplinary and biopsychosocial approach does not necessarily have to entail hospitalisation. Local services can provide transparency, short lines of communication and a better framework for interdisciplinary teams. However, this calls for increased knowledge and expertise about this group of patients at all levels of the healthcare service.

The patient and his guardians have consented to publication of this article.

LITERATURE

1. Kozlowska K. Functional somatic symptoms in childhood and adolescence. Curr Opin Psychiatry 2013; 26: 485 - 92. [PubMed][CrossRef]

2. Pareés I, Kojovic M, Pires C et al. Physical precipitating factors in functional movement disorders. J Neurol Sci 2014; 338: 174 - 7. [PubMed] [CrossRef]

3. Gjems S. Det sitter mellom ørene – Medisinsk uforklarte symptomer hos barn og unge. Tidsskr Nor Psykol foren 2016; 53: 112 - 6.

4. Gatchel RJ, Peng YB, Peters ML et al. The biopsychosocial approach to chronic pain: scientific advances and future directions. Psychol Bull 2007; 133: 581 - 624. [PubMed][CrossRef]

5. Kozlowska K, English M, Savage B et al. Multimodal rehabilitation: A mind-body, family-based intervention for children and adolescent impaired by medically unexplained symptoms. Part 1: The program. Am J Fam Ther 2012; 40: 399 - 419. [CrossRef]

6. Borrell-Carrió F, Suchman AL, Epstein RM. The biopsychosocial model 25 years later: principles, practice, and scientific inquiry. Ann Fam Med 2004; 2: 576 - 82. [PubMed][CrossRef]

7. Rusten B, Midtstigen I, Fjermestad K et al. Barn og unge med konversjonslidelser – en litteraturgjennomgang. Tidsskr Nor Psykol foren 2017; 54: 722 - 31.

8. Stewart MA. Effective physician-patient communication and health outcomes: a review. CMAJ 1995; 152: 1423 - 33. [PubMed]

Publisert: 3 September 2018. Tidsskr Nor Legeforen. DOI: 10.4045/tidsskr.18.0081
Received 23.1.2018, first revision submitted 26.5.2018, accepted 13.6.2018.