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REGULAR ARTICLE

Asylum-seeking children with severe loss of activities of daily living: clinical signs and course during rehabilitation

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Abstract

Aim: To investigate whether severe loss of activities of daily living (ADL) in asylum-seeking children is associated with physical disease or toxic influences and to describe the clinical course during the recovery process.

Methods: A total of 29 asylum-seeking children with severe loss of ADL were regularly assessed by physical examinations, laboratory tests and a structured evaluation of their ADL status during rehabilitation.

Results: A total of 12 children had previously recorded suicide attempts and 21 were recorded to have experienced traumatic events in their country of origin.

The mean time from turning point to recovery was 6 months. Of the study participants, 22 needed enteral feeding and 18 gained weight during recovery. All children had a pulse rate and systolic blood pressure within the normal range. No sign of intoxication or physical disease was identified in laboratory tests or clinical examinations, with the exception of one case of epilepsy.

Conclusion: Physical disease, pharmacological sedation or anorexia nervosa was not considered to be a probable cause of the loss of ADL in these children. The high rate of psychosocial risk factors and the stressful event of being in an asylum-seeking process call for further investigation of psychosomatic mechanisms.

INTRODUCTION

From 2002 onwards, a group of asylum-seeking children in Sweden developed a severe clinical condition with pervasive loss of activity of daily living (ADL) functions. According to a national survey in 2005, several hundred asylum-seeking children in the age range of 6–16 years were affected. This 'epidemic' was much discussed in the Swedish media and was the topic of a heated political debate in the Swedish government.

The symptoms of the children were reported to include anxiety, sleeping disturbances and depression, proceeding to a severe withdrawal behaviour in which the children lost contact with the surrounding world; did not eat, drink or move and in the most severe cases, had to be fed by nasogastric tube (enteral nutrition) (1). Bodegård (2,3) reported that the parents and siblings of these children also had psychiatric symptoms, with experiences of traumatic events in their home countries, including separation and loss of relatives. The asylum-seeking process in itself was also perceived as a stressor.

In March 2005, with 50 children in Stockholm displaying the described symptoms, a regional medical programme was organized to accomplish (i) intensive child psychiatric treatment; (ii) somatic assessment and treatment and (iii) psychiatric assessment and treatment of the parents.

The aims of this study were to describe some ADL factors, medical parameters and the recovery process of 29 asylum-seeking children, presenting the most severe loss of functions of all patients who participated in the treatment programme. We tried to answer the following questions:

- Does physical disease or other clinically identifiable physiological or toxic mechanisms explain the severe loss of ADL functions and the long recovery process?
- Are the clinical signs congruent with anorexia nervosa?
- Are the symptoms caused by sedative drugs or other toxic mechanisms?

Abbreviations

ADL, activities of daily living; DD, depressive devitalization; DSM-IV, The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders; ECG, electrocardiogram; EEG, electroencephalogram; Mobile CAP team, a mobile Child and Adolescent Psychiatry team; PRS, pervasive refusal syndrome.

PATIENTS AND METHODS

This study was carried out in the context of a multi-professional treatment programme that included the services of paediatricians from Sachs' children's hospital, a mobile child and adolescent psychiatry team (mobile CAP team) and a medical homecare team.

The paediatrician examined all children at admittance into the programme and during repeated visits to the clinic. The mobile CAP team worked with intensive family-oriented interventions and met with the family two to four times a week, in their home or at a child psychiatric day-care facility. The medical homecare team provided support to the parents with ADL activities of the children, including enteral feeding, during home visits every 3rd to 7th day. Monthly network meetings were held to secure collaboration with all caregivers. If necessary, representatives from the social services, immigration authorities or schools were invited to these meetings.

Patients

During March 2005–December 2007, a total of 70 asylum-seeking children with pervasive loss of ADL functions were included in the rehabilitation programme. Children with severe loss of ADL (defined as equal to or lower than −27 points in the structured interview presented below) during the treatment programme were included in the study. This study group comprised 29 children, 17 girls and 12 boys, aged between 7 and 19 years, with a mean age of 14.4 years. Of these, 14 were from Central Asia and six Caucasus. All children arrived in Sweden with one or both of their parent/parents; 16 arrived with a single parent. Three had no siblings, whereas the other children had one, two or three siblings. Fifteen of the children were the eldest child in the family. All children had sought asylum in Sweden when included in this study.

Background data

Background data on the child and the family history were collected in an initial interview with the parent(s) at the first contact with the child psychiatric unit; complimentary information was also collected from the parents during the treatment period. Due to the children's social withdrawal and inability to communicate, information about their exposure to trauma was obtained from the parent(s). To evaluate the information obtained, it was compared with the criteria of traumatic exposure in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).

Medical assessments

At admittance, a medical examination was conducted to identify medical causes of the child's symptoms and to evaluate threats to survival and development. A basic investigation programme was established that was used at inclusion and at follow-up visits to the clinic. This programme always included physical examination; assessment of weight, temperature, heart rate, blood pressure, blood and urine samples (see below). Additional examinations were added according to the judgement of the attending physician. If nutritional support was needed, feeding with naso-gastric tube was introduced.

During home visits, the medical homecare team assessed heart rate, blood pressure, temperature, oxygen saturation and weight, which was assessed in kilo, and thereafter plotted against the data of native Swedish children born 1974 (4). Data on height was also collected but considered unreliable as the children were assessed in bed.

ADL

To enable a systematic assessment of an individual child's psychiatric, ADL functioning, behaviour and somatic symptoms, a special assessment tool was created (Table S1). The loss of functions as well as withdrawal was described in terms of capacity to communicate, move, eat or drink and carry out daily routines. The capacity to carry out any such task was rated in a scale ranging from normal (0) to total loss of function (−7), meaning that a high negative number implicates a more severe condition. In this scale, the lowest possible score was −38.

The CAP team regularly made assessments of the child during the 1st month and later monthly and whenever the condition worsened or improved. The first measure was intended to capture baseline status. As many children lost functional ability after inclusion, the baseline level sometimes declined during their time in the treatment programme. Repeated assessments were also used to identify the turning point, i.e. the time from which the condition steadily improved. When the child had reached function level 0, i.e. when he/she had regained all lost ADL functions, the child was defined as being recovered. Recovery time is described as time from turning point to function level 0.

Laboratory examinations

Blood samples were collected at an interval between 6 and 10 weeks and urine samples were collected when needed (full blood count, C-reactive protein, erythrocyte sedimentation rate, liver function tests, kidney function tests, S–natrium, S–potassium, S–chloride, S–calcium, S–alkaline phosphatase, S–phosphatase, blood sugar level, thyroid function test, serum iron studies, S–B12, red blood cell folate and/or viral serology for testing antibody levels of HIV, hepatitis A, hepatitis B and/or urine samples). Toxicological analyses were initially only included in the investigation programme when ordered by the attending physician, but from the beginning of 2006, they were included in the routine investigation programme for all children.

In total, 16 children were examined for sedative drugs in plasma and/or in urine. In total, 22 toxicological analyses were performed on these 16 children and five children were examined more than once. Serum samples from seven of these 16 children were sent to Department of Forensic Genetics and Forensic Toxicology, National Board of Forensic Medicine, Linköping, Sweden. Blood samples were prepared with liquid/liquid extraction and analysed with gas chromatography and nitrogen-specific detection or with liquid chromatography and mass spectrometry. These

methods were used for screening and quantification of more than 80 basic drugs like antidepressants and neuroleptics, and analgesics. These methods could also detect and quantify more than 60 neutral or acid drugs like some antiepileptics and the most common sedatives and hypnotics.

Blood samples from six children and urine samples from five children were sent to Laboratories at Karolinska University Hospital and analysed for detection of sedative drugs (5–8). Serum samples from four children were sent to Analytica Chemical & Testing Services, Luleå, Sweden, for detection of bromine (9).

Ethical considerations

The Regional Ethics Research Board in Stockholm approved this study (Diarienummer 2008/1882-31/12).

RESULTS

Previous medical history

A total of eight children had a history of previous health problems and another eight had a history of previous mental health problems before arrival in Sweden. Twelve were reported to have committed suicidal attempts after arrival in Sweden. Furthermore, exposure to traumatic events and psychosocial stressors were reported; 21 of the children had traumatic experiences, according to DSM-IV criteria and 20 had suffered separation or loss of close relatives.

Clinical examinations

All children showed normal pulse rates corrected for age. However, four children had mean pulse rate values close to the upper reference interval. In these four children, 24-h electrocardiogram (ECG) monitoring showed a high mean frequency with episodes of sinus tachycardia. None showed pulse rates close to the lower reference interval and the lowest mean value was 62.

The systolic blood pressure was below the upper reference of the 90th percentile in all children, after correction for age and height. No significant changes between pulse rate and blood pressure at different time points (at inclusion, during period with the lowest level of functioning and at recovery) were observed.

Medical investigations

Six children with neurological signs of spasm or with a long period of very low level of functioning were examined with electroencephalogram (EEG) at the lowest level of functioning. One child had epileptogenic activity with bilateral spike wave activity with duration up to 4–5 sec, but no clinical symptoms during registration. All children showed EEG pattern with normal background activity and responses to stimuli.

Four children with a long period of very low level of functioning and/or a previous history of headache were investigated using computed tomography of the brain and in one child, magnetic resonance imaging of the brain was performed. All examinations were normal.

Blood and urine analyses

A total of 10 children had anaemia with low level of haemoglobin, which normalized after establishing iron supplement and sufficient nutrition intake. No other blood or urine tests were found to indicate disorder.

A total of 16 children were examined for the presence of sedative drugs in urine and/or in serum samples. None of the examinations showed the presence of any sedatives.

Level of functioning and recovery data

The mean level of functioning at inclusion in the study was −30.6 points and mean value of the lowest level of functioning was −32.6 points (for scoring see Table S1). At the lowest level of functioning, none of the children took any action for ADL. None of the children made eye contact and 28 children made no contact at all. One child nodded her head as a response to questions. Furthermore, at this time point, 22 children could not stand on their legs, whereas seven of the children could walk with the support of one or two persons.

Of the 29 children, 22 needed naso-gastric tube, whereas seven children were fed by their parent(s). At the lowest level of function, all children had swallowing function, but children with naso-gastric tube did not swallow when fed orally and rarely swallowed their saliva. The mean time with naso-gastric tube was 10.6 months (range 1.1–24.5 months). Furthermore, time with naso-gastric tube after permanent permission to stay ranged from −6.6 to 6.4 months (mean 1.4 months), which means that for some children, the enteral feeding was ended before permanent permission to stay was received.

At the lowest level of functioning, 20 children were continent for urine and faeces, three had urinary incontinence and five had urinary and faecal incontinence and for one child, data of continence are missing. All children returned to continence during recovery.

Clinical course of rehabilitation

In 22 children, the first sign of recovery was some kind of communication; to press a hand or to open the eyes, but without eye contact. The next sign was to make an eye contact, and to nod or shake the head in response to questions. When such communicative actions became more frequent, most children also actively assisted when getting fed.

After some communicative abilities were established, gross motor skills returned stepwise, from movements of arms and legs to stabilizing of head and upper body and to sitting without support, then to standing without support and finally, to walking without support. When a child had started moving, fine motor skills also returned, including feeding themselves. The ability to talk was regained last in most of the children. These last steps of the recovery process also included going back to school.

Seven children did not follow the gross motor pattern described above. Recovery time is presented in Table 1 for 28 children as one child has not yet recovered. Mean value for recovery time was 5.7 months.

Table 1 Time in programme (months) (n = 29)

	Mean	Range	SD
Time from inclusion to turning point*	7.4	1.2 to 19.8	4.2
Recovery time†‡	5.7	0.5 to 10.8	2.8
Turning point in relation to PPS	1.1	−15.0 to 16.1	5.4
Total time in programme‡§	12.6	3.6 to 22.6	4.9

PPS, permanent permission to stay.
*Turning point; the point in time after which the condition steadily improved.
†Turning point to exit from the study (to function level 0).
‡28 children included as one child has not yet recovered.
§Time from inclusion to exit from the study.

The time from having received permanent residency in Sweden to the turning point in the rehabilitation ranged from −15 to 16.1 months, which means that some children started their recovery before they had received permanent residency.

Figure 1 demonstrates the weight development of the children in the study during recovery, divided into three groups by their use of a naso-gastric tube. At inclusion, the weight was within normal limits (±2 SD) in 22, over +2 SD in two and below −2 SD in five children. These five children received naso-gastric tube during the programme. Only two had weight below −2 SD at recovery.

DISCUSSION

There were no indications that physical disorders or pharmacological agents were of importance for the severe loss of ADL functions in the asylum-seeking children investigated in this study.

No child in this study fulfilled the diagnostic criteria for anorexia nervosa according to DSM-IV (10–12). No data on weight before inclusion were available; therefore, it was not possible to evaluate the total loss of weight. However, measured weights during treatment indicate that the weight loss was less than 15% for most of the children. Furthermore, body temperature was normal, serum levels of potassium and phosphates, pulse rates and systolic blood pressure were normal. ECG monitoring in four children showed high mean frequency with episodes of sinus tachycardia as observed during stress, but no signs of QTc abnormalities or dysrhythmia.

This study was conducted during a time when important changes were made in the Swedish asylum policy in response to a strong wave of sympathy in the Swedish population for asylum children. This enabled all children in the study to receive permanent residency. It seems possible that the clinical course could have been less favourable in another time period.

We cannot completely rule out the possibility that children in the study had been exposed to sedative pharmacological agents before entering the treatment programme, or that children who were not investigated were exposed, but considering the chronic nature of this condition and the close supervision of the families, this seems most unlikely. Furthermore, EEG showed normal pattern and responses to stimuli.

Bromide has been suggested to be a possible drug used in this group of children. Bromide intoxication causes false high serum chloride level because of interference by bromide (13). However, chloride ion was analysed in serum every 6–10 weeks in all children in the programme, and was

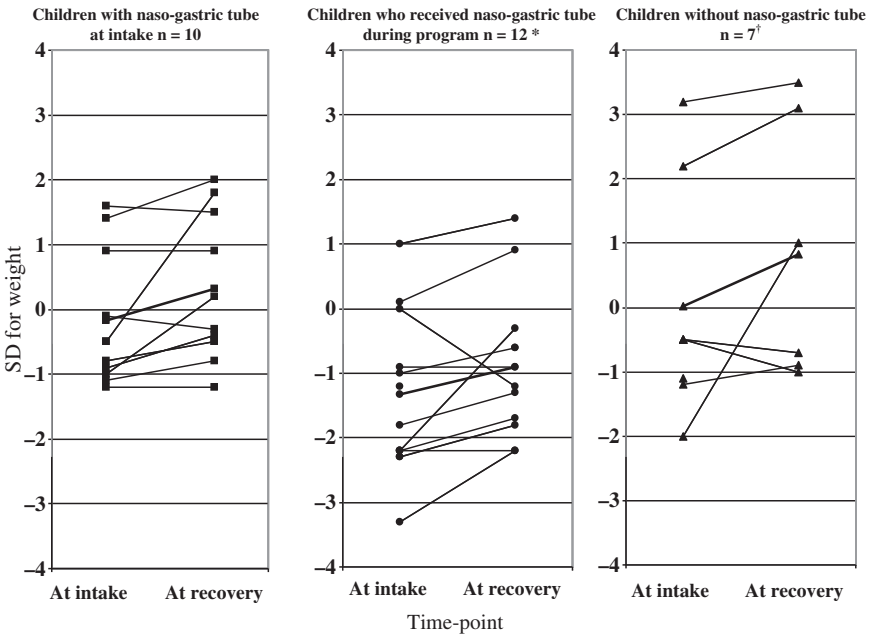

Figure 1 Weight development presented as standard deviation (SD) from normal weight curve. Children are divided into three groups by their use of a naso-gastric tube and SD values at inclusion and at recovery are presented. Values connected with thick lines demonstrate mean values of SD. *One child in this group was not assessed at exit (n = 11 at follow-up). †One child without tube has not yet left the programme (n = 6 at follow-up).

always within normal range. Furthermore, clinical signs and laboratory test results were scrutinized together with Dr Hans Persson and Dr Mark Personne, Swedish Poisons Information Centre, Karolinska hospital, Stockholm, and there were no similarities in clinical presentation to long-term use of drugs with sedative effects.

Withdrawal and loss of vital functions have previously been described in the literature as pervasive refusal syndrome (PRS) (14,15) and depressive devitalization (DD) (3). Time to recovery in PRS is described as time from initiation of treatment (admission) to recovery, with a variation from 3 weeks to 3 years (14–18). In the study describing inpatients with DD, the time interval between the date of admission and date of finishing tube feeding was concluded to vary between 4 and 34 weeks (1–8.5 months) (2). As time to recovery is defined in different ways in studies of PRS and DD, comparison is difficult. We suggest that the time from turning point to the time when the child has fully recovered, named as the recovery time in this study, is a more true reflection of the child regaining both physiological and psychological wellbeing.

The recovery process was long-lasting and followed a similar pattern in most children, suggesting that this condition affects brain functions in a profound way. The high load of previous psychosocial stress with frequent traumatic events, separation and loss before arrival in Sweden and the fact that all children developed their symptoms during or shortly after their application for asylum was being processed by the Swedish authorities suggest that stress may be an important factor in the development of severe loss of ADL in the children in this study. Further investigations are needed to test these hypotheses in analyses of relevant neuro-humoral markers.

In conclusion, there was no indication of physical disease or pharmacological/toxic sedation as a cause of the severe loss of ADL functions in the 29 asylum-seeking children in this study.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

Table S1 Checklist for assessing level of functioning (points).

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