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Forslund, Carl-Magnus; Johansson, Björn Axel

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Pervasive refusal syndrome among inpatient asylum-seeking children and adolescents – a follow-up study

Carl-Magnus Forslund, MD ✉

Psychiatry Skåne
Department of Child and Adolescent Psychiatry
Open Care Unit
Cronqvists gata 124
Skåne University Hospital
S-205 02 Malmö
Sweden

e-mail; carl-magnus.forslund@skane.se
Telephone; +46730652107
Fax; +4640336253

Björn Axel Johansson, MD, PhD

Clinical Health Promotion Centre,
Department of Health Sciences, Lund University, Lund and
Psychiatry Skåne
Department of Child and Adolescent Psychiatry
Emergency Unit
Cronqvists gata 128
Skåne University Hospital
S-205 02 Malmö
Sweden

e-mail; bjorn_axel.johansson@med.lu.se

Telephone; +46736250678

Fax; +4640333269

Abstract

Background: Pervasive refusal syndrome (PRS) is a rare but severe condition, characterised by social withdrawal and a pervasive active refusal in terms of eating, mobilisation, speech and personal hygiene. PRS has been proposed as a new diagnostic entity in child and adolescent psychiatry, although the diagnostic criteria are debated. In the past ten years there has been an increase in PRS symptoms among asylum-seeking children and adolescents in Sweden. Here we describe five cases of PRS among asylum-seeking children and adolescents. **Method**: 3 females and 2 males, 7-17 years of age with the clinical picture of PRS, treated as inpatients at the Department of Child and Adolescent Psychiatry, Malmö, Sweden, 2002-2010, were analysed on the basis of their medical records. Subjects were diagnosed using previously suggested criteria for PRS. At follow-up, a semi-structured interview focusing on the inpatient stay and current status was performed. The subjects were assessed with Global Assessment of Functioning (GAF) and self-rating questionnaires regarding depression and post-traumatic stress disorder (PTSD). **Results**: The pattern of refusal varied among the five subjects. All subjects originated from former Soviet republics, indicating a possible cultural factor. Mean period of inpatient treatment was five months. All subjects received intense nursing and were treated with nasogastric tube feeding. Parents were involved and were given support and instructions. All subjects gradually improved after receiving permanent residency permits. Depression and PTSD were co-morbid states. At follow-up, 1-8 years after discharge, all subjects were recovered. **Conclusion**: Although a severe condition, our five cases suggest a good prognosis for PRS among asylum-seeking children and adolescents.

Keywords; Pervasive refusal syndrome, asylum-seeking, adolescents, follow-up, prognosis

Background

Pervasive refusal syndrome (PRS) among children and adolescents, introduced by Lask et al. (1991), is a rare but potentially life-threatening condition. PRS is characterised by social withdrawal, school refusal, a profound and pervasive refusal within different domains relating to everyday activities, e.g. eating, mobilisation, communication and attention to personal care [1]. PRS is a relatively new concept. The literature on the topic is rather limited with only 15 articles (24 cases) identified in the review by Jaspers et al. (2009) [2]. A search at PubMed.com (August 2012), using the term "Pervasive Refusal Syndrome", revealed 7 additional articles (10 cases) published after 2009. The complex set of symptoms cannot be accounted for by any of the diagnoses in DSM-IV or ICD-10 [1-3]. In the upcoming DSM-5 classification system available for discussion on the Internet, PRS is not mentioned [4]. In 1997 Thompson & Nunn suggested diagnosis criteria [3], which were adapted by Jaspers et al. (2009) [2] (Table 1). In this adaptation the previous separate criteria of "clear food refusal and weight loss" were attached to criteria A as suggested by Jaspers et al., since the refusal in PRS was considered more diverse and not mainly restricted to food refusal and its consequence of weight loss [2].

All criteria (A-F) must be fulfilled for the diagnosis of PRS [2]. To our knowledge no validated questionnaires for the diagnosis of PRS are available. PRS predominantly affects girls (75%) [2]. Pre-morbid personality, e.g. perfectionist, conscientious and high achievers, previous emotional and behavioural disturbances and parental psychiatric problems are important risk factors [1-3, 5]. The importance of early trauma, e.g. witnessing of violence and sexual abuse, are considered to be precipitating events [1-3, 5]. The concepts of "learned helplessness and hopelessness" and "lethal mothering" has been used as explanatory models of PRS [6, 7]. One study suggests that PRS can be caused as an autoimmune post-infectious disorder of the brain [8]. Common co-morbidities and differential diagnoses are depression, anxiety disorders and somatoform disorders [2]. PRS has not been identified among adults, who nevertheless can present active refusal and resistance as an expression of regression as a part of psychiatric illness [2].

No evidence-based treatment for PRS is known. Most authors agree that inpatient care is often required, although there have been cases successfully treated at home [1-3, 5]. Jaspers et al.

(2009) suggest a comprehensive multidisciplinary team approach, involving tender loving care [2]. The family has an important but complicated role in the treatment. Family involvement relieves anxiety, but over-involvement is considered counterproductive [2]. Medication seems to play a limited role, but could be useful in treating specific co-morbidities, while nasogastric tube feeding is almost always required [2, 5]. Jasper et al. (2009) report a mean duration of treatment of 12.8 months, with complete recovery in 67% and partial recovery in 25% of cases [2]. In a study by Guirguis et al. (2011), the authors found complete recovery in two of three cases, 3-16 years after discharge [9]. In a Danish study from 2011, one case of PRS is described who, at follow-up, was fully recovered six years after discharge [10].

A clinical picture resembling PRS was reported from 2002 and onwards among traumatised asylum-seeking children and adolescents in Sweden [7, 11-13]. These cases presented active and angry refusal, the core feature of PRS, but more often a more passive resistance. The most severe cases were postulated as being identical to PRS and responded well to treatment proposed for PRS by Thompson and Nunn (1997) [3, 12]. When describing these children Bodegård (2004) introduced the term 'Depressive Devitalisation' (DD) [7, 11]. These children attracted much attention in the Swedish media and were referred to as the "apathetic children" or children with "symptoms of hopelessness/resignation" or "Giving-up" syndrome. The incidence is not available since the definition of apathetic children has varied greatly. In the medical literature, Bodegård reported 16 cases of DD in the Stockholm area 2002-2004 [14]. In 2006 Von Folsach and Montgomery addressed the differences and similarities between PRS and DD and suggested that DD and PRS were different subgroups within the same refusal syndrome [14]. Depression and post-traumatic stress disorder (PTSD) is common among children and adolescents in a refugee population, and comprise significant differential diagnoses to PRS and DD [2, 14, 15].

At the treatment ward of the Department of Child and Adolescent Psychiatry, Malmö, Sweden, we have seen an increase in the numbers of asylum-seeking families in the past ten years, including a small but challenging subgroup of children and adolescents with the clinical picture of PRS. In addition to previously suggested treatment [2], we have developed a treatment method involving stimulation of the various senses. In brief, this involves an individualised programme, where patients are exposed to taste-teasers (e.g. ice-cream, fruits), scents, massage, music and books in the patients' native language on a weekly basis. The

parents receive instruction and are encouraged to gradually take a more active role in the treatment.

The main objective of this study was to describe the clinical picture of PRS among asylum-seeking children and adolescents, including a follow-up with screening questionnaires and a semi-structured interview.

Method

Asylum-seeking subjects with a clinical picture of PRS, treated as inpatients at the treatment ward of the Department of Child and Adolescent Psychiatry in Malmö in the period 2002-2010, were identified through interviews with senior colleagues and studies of patient administrative files. In this period, 274 patients were treated at the ward. Twenty-nine patients (11%) were asylum-seeking subjects. Seven subjects presented a clinical picture of PRS. One case, originating from Syria, was treated for presumed PRS for six weeks, but was later diagnosed with neurofibromatosis type 2 and was excluded from the study. Another case, originating from Armenia, met criteria A-D and F for PRS [2], but after a complete analysis of her medical records, the clinical picture was explained by PTSD with a co-morbid depression, and she was therefore excluded. Five subjects were included in the study. Exclusion criteria were somatic illness and/or severe psychiatric disorder, e.g. major depression, psychotic disorders.

Initially, seven subjects were enrolled and contacted by mail (in both Swedish and their native language) and by telephone. After informed consent had been given, the hospital stay was analysed from their medical records, and the ICD-10 diagnoses, set by a senior physician at discharge, were retrieved. A semi-structured interview (Appendix) was conducted in the subject's home, in a neutral location or by telephone, as preferred by the subjects. The first part of the interview addressed the subject's view of the hospital stay (14 questions). The second part focused on current mental health and functioning (9 questions). No validated questionnaire was found for the follow-up interviews so we developed a questionnaire guided by previous research on PRS and DD [2, 7, 9, 11-12, 14]. The questionnaire was internally validated through ward personnel. During the interview, the subject's function based on Global Assessment of Functioning (GAF) was evaluated [16]. The subjects were asked to

complete the Montgomery Åsberg Depression Rating Scale – self-rating version (MADRS-S) and PTSD Checklist – Civilian Version (PCL-C) [17-18]. Data concerning the asylum-seeking process was obtained from the Swedish Migration Board by personal contact via telephone and mail with a statistical administrator [19]. Participation in the project was voluntary and subjects were able to withdraw without giving a reason. The subjects were offered an additional follow-up telephone contact in case of any possible reactions after the interview. The project was approved by the Regional Ethical Review Board at Lund University.

Results

Demographics

Three of the five subjects were female. Mean age at admission was 13.6 (7-17) years. All subjects were asylum seekers from former Soviet republics, belonging to a political and/or ethnic minority. No information regarding religion could be retrieved from the medical records. All subjects had siblings. In Case 3 the father was in prison in Azerbaijan, in Case 4 siblings arrived in Sweden after discharge from hospital. Parents described Cases 1 and 4 as high achievers and conscientious, and Case 3 as conscientious before arriving in Sweden. Cases 2 and 5 had a history of depression and PTSD respectively before arriving in Sweden. All subjects were traumatised to various extents. All families had applied for permanent residency permit (PRP) at least once prior to admission. Mean time from the first application to the granting of PRP was 2.2 (1.2-3.5) years (Table 2). Interpreters were used consistently during the inpatient stay but could, for practical and economic reasons, not be involved all the time, which sometimes led to linguistic misunderstandings. However, these misunderstandings could usually be resolved later.

Inpatient stay

Reasons for admission were “giving-up” syndrome, apathy, suicide attempt and refusal to eat and speak. The onset was typically gradual, but in Cases 2 and 3 there was rapid deterioration prior to admission. Case 4 had a very rapid onset, with development of all symptoms within hours of arriving in Sweden. All cases presented a clinical picture of PRS, with complete refusal in all four domains [2]. The refusal pattern differed among the subjects and varied during the inpatient stay. Case 1 presented passive resistance initially, but a clear active and

angry refusal during most of the inpatient stay. Cases 2, 3 and 5 presented a mixed picture of both active refusal, e.g. actively biting lips together and turning head to the side when fed, and passive resistance. Case 4 showed a more consistent passive resistance. All subjects underwent a physical examination, where Case 4 presented a transient slight side-difference in motor tonus. In addition to routine and toxic blood and urine analysis, extended somatic assessment was performed for all subjects without pathological outcome. All subjects received intensive nursing, physiotherapy and sensory stimulation. In all cases, supportive and instructive discussions were held with the parents. In Cases 2-5, one or both parents were referred for psychiatric evaluation, either to a general psychiatrist or to a team specialised in war and torture injuries. All subjects were treated with nasogastric tube feeding, with a mean duration of 27 (10-60) weeks. When the patient had not eaten for 2-3 days, tube feeding was started in consultation with paediatrician. When the patient gradually improved, daily attempts were made by feeding per os. When the patient could eat sufficiently, the nasogastric tube feeding was stopped. Cases 1-3 and 5 were treated pharmacologically, using antidepressants and anxiolytics in treating their co-morbidity. The subjects improved gradually after PRP as shown by, for example facial expressions after three weeks and eating small portions after a month, in all cases with temporary setbacks. Case 4 was discharged with continued nasogastric tube feeding administered by the parents at home for 7.1 months. Mean treatment time was 5.1 (3.2-8.5) months. Time to recovery measured as time from admission to discharge from outpatient care was 15.3 months (Table 2).

Interview – inpatient stay

In Cases 3 and 4 the interview was held face-to-face with parents present, while in the remaining cases the interviews were held by telephone with the subjects. In Cases 2 and 5 we also talked to the parents. Case 2 only wished to respond to the second part (current state) of the interview. Mean age at follow up was 18 (16-21) years and mean time since discharge from inpatient care was 3.6 (1-8) years (Table 3).

All subjects reported varying degrees of memory loss about their inpatient stay. In Case 4, where the subject had complete memory loss, information was obtained from her parents. Case 3 clearly remembered the active refusal during eating. Case 5 remembered his parent's reaction, fear and worry about his illness. The subjects' view of the onset varied, reporting different factors causing their illness. Cases 1 and 5 emphasised their parents' role during the inpatient stay as being an important support, while Case 3 was indifferent to this. All cases

had a positive experience of their inpatient stay. Different factors were reported as contributing to improvement. Cases 1, 3 and 5 reported PRP as important for recovery. On the subjects' view of the treatment, Case 1 had wanted more activities, while Case 3 had wanted fewer activities. All subjects reported a gradual and slow recovery process. Case 4 experienced a more rapid improvement once her siblings arrived in Sweden. For future PRS patients, Cases 1, 3 and 4 emphasised the importance of involving the parents/family in the treatment and an encouraging atmosphere with mutual communication between the family and care providers. Case 4 also emphasised the importance of an interpreter and temporary leave as way of normalising the condition during the course of treatment (Table 3).

Interview – current state

At follow-up, all subjects were recovered, with good psychosocial functioning. All subjects attended school/university. They all thrived in their social environment, had normal age-appropriate leisure interests and had contact with their parents and siblings. Cases 1 and 5 were also in part-time employment. Cases 1, 2 and 5 reported mild psychiatric symptoms, e.g. mild insomnia. After follow-up, outpatient treatment, none of the subjects reported any subsequent contact with psychiatric care. All had a positive view of their future with ambitious plans to enter higher education. Case 1 had a child. All subjects declined the extra follow-up telephone call (Table 3).

GAF and self-rating questionnaires

Mean GAF score at follow-up was 72 (70-75). Screening questionnaires were obtained from four subjects. Mean MADRS-S score was 7.8 (0-15), and mean PCL-C score was 28 (20-36). In Case 2 the MADRS-S score of 15 (0, 2, 3, 0, 2, 4, 1, 2, 1) indicated a mild depression but, after analysing the individual items, data from the interview, together with the ICD-10 criteria, she did not meet the diagnostic criteria for a depressive episode. None of the cases had PTSD according to PCL-C and ICD-10 (Table 3).

Discussion

PRS is a relatively new concept with only a few studies published on the topic. In the present study, we describe five cases of PRS among asylum-seeking children and adolescents. The

main findings were varying patterns of refusal, possible cultural factors, PRP as a healing factor, and a positive prognosis.

Diagnostic concerns

None of the ICD-10 diagnoses given to the patients could fully explain the clinical picture, which corresponded better to PRS or DD [2, 14]. Jans et al. (2011) argued that the pattern of refusal in PRS is a continuum ranging from an active refusal to passive resistance, suggesting a slight modification of the diagnostic criteria in PRS [20]. We also found a continuum of refusal pattern among our cases, supporting the diagnostic modification suggested by Jans et al. (2011). Applying this to our material we consider our five asylum-seeking cases to be a subgroup of PRS.

Cultural factors

In 2002-2010, refugees from former Soviet republics constituted 14% of the total asylum-seeking population in Sweden [19]. Among asylum-seeking children and adolescents in Sweden, PRS and DD are over-represented among subjects originating from former Soviet republics, indicating cultural aspects [11-12, 14, 21]. In a government report from 2006 on children and adolescents with various symptoms of DD and "symptoms of hopelessness/resignation", Ahmadi (2006) argued that people from these countries, e.g. Azerbaijan, have a "holistic approach" where children in some cases could act as patrons for the collective, i.e. the family, and use the resources available for collective survival [22]. However no evidence was found of a direct relationship between cultural characteristics and the development of "symptoms of hopelessness/resignation" [22].

Asylum-seeking process

The concept of learned helplessness and hopelessness has been proposed as an explanatory mechanism of PRS [6]. Nunn and Thompson (1996) argued that PRS develops in the interaction between child and parents as a response to events that are perceived as uncontrollable, e.g. any form of abuse, witnessing violence, and migration [6]. This model is applicable to our material, where trauma as well as a stressful asylum-seeking process could be looked upon as uncontrollable events [23]. Compared to the average asylum-seeking processing time in Sweden of 0.8 years [24], our cases had an extended process, with a mean time of 2.2 years. The sense of hopelessness is probably exacerbated by an extended asylum-seeking process, which is known as a risk factor for psychiatric disorders [23]. In a Swedish

study from 2005, Joelsson and Dahlin illustrated the asylum-seeking process as a contributing factor for the development of DD [21]. This is also reflected in the role of PRP as an important starting point for recovery, which was also seen in our material [13, 21, 25]. In summary, the asylum-seeking process is probably an etiological factor for PRS among asylum-seeking children and adolescents, which distinguishes them from non-asylum-seeking children with PRS.

The retrograde amnesia, to our knowledge not previously reported among PRS-patients, could be explained by dissociation related to trauma and possible imbalance of endogenous stress hormones [26-27]. However our study design did not allow for any specific investigation of this matter.

Prognosis

The prognostic data was supported by the results of MADRS-S and PCL-C, which to our knowledge has not previously been used at follow-up of PRS. At follow-up, all cases were recovered, indicating a better prognosis among asylum-seeking children and adolescents compared to non-asylum-seeking children and adolescents with PRS [2]. We believe that the impact of an extended asylum-seeking process is important for the development of PRS in this subgroup. When this factor is corrected or reduced by PRP, it could result in a better prognosis in the asylum-seeking population compared with non-asylum-seeking children who do not experience the same dramatic change in social context. The asylum-seeking process could therefore be considered both a risk factor, associated with the development of PRS, and a good prognostic factor, in case of a positive decision.

A majority of cases emphasised the importance of involving the family in the treatment and an encouraging and positive atmosphere with mutual communication between the family and care providers. In line with previous reports on PRS we believe that the family has an important role in the course of therapy [2]. It is therefore important that parents and siblings receive support and instruction, and psychiatric treatment of their own when needed.

Limitations

The small number of subjects makes it difficult to draw general conclusions. Since PRS is a relatively new concept no validated questionnaires or structured interviews are available for the diagnosis of PRS, which in this retrospective study represents a limitation. This also causes methodological consequences, as different measuring instruments were used at

admission and at follow-up. Our intention was to meet all subjects face-to-face, but 3/5 chose the telephone option, limiting the accuracy for assessment with GAF. In one case some data was collected from parents. Despite the limitations, we consider the five cases as an important contribution to the field of PRS.

Conclusion

Due to varying patterns of refusal, we support previous suggestions on modifying the diagnostic criteria of PRS. The possible impact of cultural aspects requires further research. PRP seem to be healing factor. Results suggest a good prognosis of PRS among asylum-seeking children and adolescents.

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Conflicts of Interest

The authors declare that they have no conflict of interest.

References

1. Lask B, Britten C, Kroll L, Magagna J, Tranter M (1991). Children with pervasive refusal. Arch Dis Child 66(7):866-969.
2. Jaspers T, Hanssen GM, van der Valk JA, Hanekom JH, van Well GT, Schieveld JN (2009). Pervasive refusal syndrome as part of the refusal-withdrawal-regression spectrum: critical review of the literature illustrated by a case report. Eur Child Adolesc Psychiatry 18(11):645-651.
3. Thompson SL, Nunn KP (1997). The pervasive refusal syndrome: the RAHC experience. Clin Child Psychol Psychiatry 2:145-165.
4. American Psychiatric Association. DSM-5 Development. Psych. Org http://www.dsm5.org. Accessed 15 May 2012.
5. Lask B (2004). Pervasive Refusal Syndrome. Adv Psychiatric Treat 10:153-159.
6. Nunn KP, Thompson Sl (1996). Pervasive refusal syndrome: learned helplessness and hopelessness. Clin Child Psychol Psychiatry 1:121-132.
7. Bodegård, G. (2005). Life threatening loss of function in refugee children: Another expression of pervasive refusal syndrome? Clin Child Psychol Psychiatry 10:337–350.
8. Wright B, Beverley D (2011). Pervasive Refusal Syndrome. Clin Child Psychol Psychiatry. [Epub ahead of print] 6 July, 2011, doi: 10.1177/1359104511403680.
9. Guirguis S, Reid C, Rao S, Grahame V, Kaplan C (2011). Follow-up study of four cases of pervasive refusal syndrome. Eur Child Adolesc Psychiatry 20(5):271-274.
10. Christensen AM, Thelle T (2011). Afvisningssyndrom hos en 12-årig dreng [Refusal syndrome in a 12-year-old boy]. Ugeskr Laeger 18;173(16-17):1214-1215.
11. Bodegård, G (2004). Asylsökande flyktingbarn utvecklar livshotande funktionsbortfall [Asylum-seeking children develop a life-threatening lack of function]. Läkartidningen 101, 1696–1699.
12. Bodegård G (2005). Pervasive loss of function in asylum-seeking children in Sweden. Acta Paediatr 94(12):1706-1707.
13. Aronsson B, Wiberg C, Sandstedt P, Hjern A (2009). Asylum-seeking children with severe loss of activities of daily living: clinical signs and course during rehabilitation. Acta Paediatr 98(12):1977-1981.
14. Von Folsach LL, Montgomery E (2006). Pervasive refusal syndrome among asylum-seeking children. Clin Child Psychol Psychiatry 11(3):457-473.
15. Heptinstall E, Sethna V, Taylor E (2004). PTSD and depression in refugee children: associations with pre-migration trauma and post-migration stress. Eur Child Adolesc Psychiatry 13(6):373-80.
16. American Psychiatric Association. (2000). Diagnostic and statistical manual of mental disorders – DSM-IV-TR. Washington DC; Author.
17. Bondolfi G, Jermann F, Rouget BW, Gex-Fabry M, McQuillan A, Dupont-Willemin A, Aubry JM, Nguyen C (2011). Self- and clinician-rated Montgomery-Asberg Depression Rating Scale: evaluation in clinical practice. J Affect Disord 121(3):268-72.
18. McDonald SD, Calhoun PS (2010). The diagnostic accuracy of the PTSD checklist: a critical review. Clin Psychol Rev 30(8):976-87.
19. Personal contact with Hans Nidsjö, statistical administrator. Swedish Migration Board, Planning and Control, Norrköping, Sweden. (hans.nidjso@migrationsverket.se).
20. Jans T, Ball J, Preiss M, Haberhausen M, Warnke A, Renner TJ (2011). Pervasive refusal syndrome. Three German cases provide further illustration. Z Kinder Jugendpsychiatr Psychother 39(5):351-358; quiz 359.

21. Joelsson L, Dahlin K (2005). Asylprocess grogrund för apati hos vissa barn [Asylum-seeking process a breeding ground for apathy among certain children. A negative decision concerning the residence permit is often a triggering factor]. Läkartidningen 102(48):3646-50.
22. Ahmadi N (2006). Asylsökande barn med uppgivenhetssymtom – trauma, kultur, asylprocess [Asylum-seeking children with symptoms of resignation – trauma, culture, asylum process]. Statens offentliga utredningar SOU 2006:49. Edita, Stockholm.
23. Robjant K, Hassan R, Katona C (2009). Mental health implications of detaining asylum seekers: systematic review. Br J Psychiatry 194(4):306-12.
24. Swedish Migration Board (2009). Migrationsverket statistik 2009-02-18, Tabell 1 2008 [Swedish Migration Board, Statistics 2009-02-18, Table 1]
25. Ascher H, Gustavsson T (2008). Clearing conference about children with refusal symptoms. Läkartidningen 9-15;105(1-2):31-3.
26. Markowitsch HJ (2003). Psychogenic amnesia. Neuroimage Nov;20 Suppl 1:S132-8.
27. Söndergaard HP, Kushnir MM, Aronsson B, Sandstedt P, Bergquist J (2012). Patterns of endogenous steroids in apathetic refugee children are compatible with long-term stress. BMC Res Notes 19;5:186.

Tables

Table 1 – Diagnostic criteria for PRS according to Jaspers et al. (2009) [3].

A.	Partial or complete refusal in three or more of the following domains: (1) eating, (2) mobilisation, (3) speech, (4) attention to personal care
B.	Active and angry refusal to acts of help and encouragement
C.	Social withdrawal and school refusal
D.	No organic condition accounts for the severity of the degree of symptoms
E.	No other psychiatric disorder could better account for the symptoms
F.	The endangered state of the patient requires hospitalisation

Table 2 – Demographics, inpatient stay and outpatient treatment

Demographics	Case 1	Case 2	Case 3	Case 4	Case 5
Sex	Female	Female	Male	Female	Male
Age on admission	16	15	17	13	7
Nationality	Azerbaijan	Azerbaijan	Azerbaijan	Azerbaijan / Russia	Azerbaijan
Pre-morbid personality	High achiever, conscientious	-	Conscientious	High achiever, conscientious	-
Prior somatic illness	Hepatitis	-	Cerebral concussion	-	Epilepsy
Prior psychiatric illness	-	Depression	-	-	PTSD
Trauma (psychosocial / witnessing sexual violence / being beaten)	+ / + / +	+ / - / -	+ / + / +	+ / +/ -	+ / - / -
Years to PRP	1,8	3,5	2,4	1,2	2,2
No. of PRP-rejections	4	7	3	1	1

Inpatient Stay

Cause of admission	"Giving-up" syndrome	Suicide attempt	Suicide attempt	Apathy	Refusal regarding eating and speech
ICD-10 diagnoses at admission	-	-	X70.80	R45.3	-
GAF at admission	10	10	30	10	20
PRS Onset	Gradual	Gradual – rapid[a]	Gradual – rapid[a]	Rapid	Gradual
Refusal pattern (active / passive)	+ / +	+ / +	+ / +	- / +	+ / +
Somatic assessment	Cerebral CT-scan, EEG	Cerebral CT-scan, paediatrician consultant	Cerebral CT-scan, EEG, ECG	EEG[b]	Paediatrician consultant
Tube feeding duration (weeks)	10	26	28	60	10
Medication	Alimemazine	Alimemazine	Mirtazapine	-	Sertraline, Alimemazine
Duration of treatment (weeks)	15	29	37	17	14
ICD-10 diagnoses at discharge	R45.3 F94.0	R45.3	F32.2 F43.1	R45.3	F32.2 F43.1 F43.2

Outpatient treatment

Follow-up at outpatient clinic	Yes	Yes	Yes	Yes, with tube feeding	Yes
Time from admission to end of outpatient care (weeks)	28	41	54	92	118

Table 3 – Follow-up

Interview	Case 1	Case 2	Case 3	Case 4	Case 5
Setting	Telephone	Telephone	Neutral location	Subject's home	Telephone
Age at follow-up	21	19	18	16	16
Time since discharge (years)	4	3	1	2	8

Part I – Inpatient stay

Memory loss	Partial	-	Partial	Complete	Partial
Experience of onset	Gradual	-	Gradual	Rapid[c]	Gradual - rapid[a]
Contributing factors for PRS onset	Don't want to talk about it	-	Trauma. Fear of returning to Azerbaijan	Stress[c]	Fear of returning to Azerbaijan
Experience of sensory stimulation	Don't remember	-	Positive	Positive[c]	Don't remember
Contributing factors for recovery	Support from mother. PRP	-	PRP	Temporary leave. Family reunion. Sensory stimulation. School[c]	Physiotherapy, PRP

Part II – Current state

School / work	+/+	+/-	+/-	+/-	+/+
Psychiatric symptoms	Some sadness when thinking of the past	Mild insomnia	None	None	Mild insomnia Hyper-arousal
Somatic symptoms	Intermittent headache	None	None	None	None

GAF and self-rating questionnaires

GAF	70	70	75	75	70
MADRS-S	-	15/54	0/54	4/54	12/54
PCL-C	-	36/85	21/85	20//85	35/85

Legends

Table 1 – Diagnostic criteria for PRS according to Jaspers et al. (2009) [2]

PRS = Pervasive Refusal Syndrome

Table 2 – Demographics, inpatient stay and outpatient treatment

PTSD = Post-Traumatic Stress Disorder

GAF = Global Assessment of Functioning

CT = Computed Tomography

EEG = Electroencephalography

ECG = Electrocardiography

ICD = International Classification of Diseases

PRP = Permanent residency permit

PRS = Pervasive Refusal Syndrome

[a] = Initially gradual onset with a rapid deterioration prior admission

[b] = Parents declined cerebral CT scan

Table 3 – Follow-up

PRS = Pervasive Refusal Syndrome

PRP = Permanent residency permit

GAF = Global Assessment of Functioning

MADRS-S = Montgomery-Åsberg Depression Rating Scale – Self-rating version

PCL-C = PTSD Checklist – Civilian Version

[a] = Initially gradual onset with a rapid deterioration prior admission

[c] = Information from parents

Appendix

Part I – Questions concerning inpatient stay

1. Do you remember the time at the hospital?
2. How would you describe your inpatient stay?
3. Could you think of any factors contributing to your illness?
4. Do you remember the onset as a gradual or rapid process?
5. Do you remember your parents' reaction to your illness?
6. In what way did your parents affect you during your inpatient stay?
7. What is your opinion of the care given at the ward?
8. Did you feel anything was lacking in the treatment?
9. Was there anything regarding treatment that could have been better?
10. How did you experience the treatment with stimulation of the senses?
11. Do you remember any factors contributing to your improvement?
12. Do you think of your improvement as a gradual or rapid process?
13. Was your permanent residency permit an important factor contributing to your recovery?
14. Do you have any advice to us as care providers to consider next time we treat a patient with Pervasive Refusal Syndrome?

Part II – Questions on current state

1. How have you felt during the past 2 weeks?
2. Are you happy with your social environment?
3. Do you have an occupation or are you studying?
4. What do you do in your spare time?
5. Do you have any somatic or psychiatric symptoms?
6. Have you had any subsequent contact with any care providers after discharge?
7. If so, what treatment did you receive?
8. Do you have any current contact with a psychiatric department?
9. How do you see your future?