

Comment on the paper “Pervasive Refusal Syndrome (PRS) 21 years on—a reconceptualization and renaming” by Ken Nunn, Bryan Lask and Isabel Owen

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In the first years of the twenty-first century an increasing number of children in Sweden developed loss of physical and mental functions without underlying physical disorder. In some, it progressed to life-threatening “depressive devitalisation” [2, 3]. These children came from severely traumatized asylum-seeking families, mostly ethnical minorities from central Asian former soviet republics. The condition seemed to be rather similar to pervasive refusal syndrome (PRS) [2, 3], which is a generally possible reaction of children in dysfunctional family situations and overloaded with trauma. Because of my own long experience as a paediatrician and child psychiatrist, and my personal clinical experience with those severely ill children, I had—and still have—no reason to question that the Swedish “apathetic children” manifest an expression of PRS.

The works of Lask and Nunn from the 1990s introduced the PRS concept and this caused bewilderment, questioning and a lasting debate. In their present paper, the straggly global apprehensions of PRS are discussed and a neurobiological explanatory theory is presented which motivates a reconceptualization of PRS and the new designation Pervasive Arousal Withdrawal Syndrome (PAWS).

The explanatory theory describes how the hyper-aroused sympathetic and parasympathetic systems are left in a lasting deadlock, causing an ominous loss of both physical and psychical homeostasis. This accounts for the

conglomeration of unintelligibly contradictory active and passive symptoms, manifested in, e.g., in an increase of body temperature, fixed tachycardia, periods of profuse sweating and hyperventilation. The stuporous state is interrupted by panicky anxiety attacks when external or internal stressors exceed the child’s seemingly compact barriers and cause flashbacks or nightmares. The complete loss of muscular tonus is interrupted by hypnagogic twitching [1].

The accumulation of hundreds of children in Sweden with symptoms corresponding to PRS created a possibility for scientific standardized studies. This opportunity was, however, seriously distorted. The Ministry for Migration and Asylum Policy—not the Ministry of Health and Social Welfare (!)—initiated a nationwide survey which identified an odd number of 400 cases. The questionnaire used was flawed by the lack of questions regarding the background, including possible traumatic factors. The National Board of Health and Welfare allied with the leaders of the child psychiatric society, and regarded the situation as an *epidemic* of reactive group behaviour in asylum-seeking families. It was asserted that similar situations were not known for asylum-seeking families in other countries, and that the condition was not described earlier. These families had no formal refugee status and were in the dual situation of threat of deportation and a prospect of secondary gain of illness (i.e., residence permit). It was stressed that possibilities of manipulation and malingering should be considered. The available knowledge regarding psychotraumatic research and children’s behaviour in war zones was not respected by the political establishment. Any relation to the PRS was rejected with the motivation that “*the cases described in the international literature do not include refugees or ethnical minorities*” [4]. (Normal) medical attention was claimed to increase risks for psychic

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contagiousness and hospital care was said to deteriorate the withdrawal condition. Treatment should focus on enhancing the parents' own responsibility for their children's health [5] and the children were not regarded ill in the ordinary sense. The whole affair was not considered the health care system's responsibility. The majority of the child psychiatric establishment preferred this "politically correct" stance. The behaviouristic "no-care" approach was never founded by any reported studies neither before nor later. The official stance turned out to be destructive for the medical scientific, clinical and ethical perspectives and caused great difficulties for clinical work based on ordinary medical principles. Moreover, it led to an increase in deportation of very severely disabled children without attention to continuity of the treatment. There was explicit obstruction of scientific studies and the situation evoked a wild debate with participants embarrassingly lacking adequate experience.

The intense media attention was claimed to induce other asylum-seeking families to imitate the syndrome which could grant an application for residence permit motivated by the state of ill health. The psychic contagion was considered to explain the "epidemic" [6]. It was, however, not considered that more than half of the identified cases had fallen ill before the media had focussed their attention to the situation, and that the affected families were scattered all over the country and could not easily be reached by the media. The mass media attention was anyway very contagious and created a public opinion that the "epidemic" was related to parental manipulation, thus a form of child abuse [7].

The situation in Sweden anyhow generated a substantial amount of valuable experience and clinical reports pointed out the "depressive devitalisation" to be a form of PTSD with similarities to PRS [2, 3]. Treatment based on medical assessment was superior to the settled behaviouristic corrective approach [8]. These clinical studies were considered anecdotic, however, and not of interest since the authorities had decided that these families should not have access to hospital care [8]. Our reports overwhelmingly support the now presented neurobiological explanatory theory as the relevant theoretical foundation and the PAWS as a consequent redesignation of the syndrome.

The "Refusal" concept has been of essential importance in the international discussions about PRS. Bodegard [2] reported already in 2004 that the refusal in "depressive devitalisation" had the character of terrified fear rather than intent which was further elaborated in our report of a group of 33 cases in 2008 [1]. The quality of fear of the refusal is stressed in the present paper by Lask et al. indicating the condition to be a complex manifestation of PTSD.

Traumatic burden In our 2008 report, we describe 31 cases and demonstrate the traumatic burden and its

relation to the time of falling ill and duration of the need for advanced medical treatment [1]. Half of the children fell ill before they were hit by any possible traumatization following rejection of the Swedish residence permit application. This also was the case for the entire group of 400 children. The children with a heavier traumatic burden at arrival in Sweden fell ill more rapidly than the ones developing the syndrome later. The most significant traumatic experiences were exposure together with the mother to killing and witnessing sexual abuse and rape, threat and physical or sexual violence directed to the child [1].

Premorbid personality and the family Our observations prove the impact of the intricate and lengthy reciprocity between

- *the background* of the premorbid personal sensitivity of the child in the dysfunctional family climate permeated by hopelessness, helplessness, and uncontrollability
- *the substantial traumatic experiences* from the event initiating the family's flight
- *the harmful influence of the questioning attitude in the society*, and the health care system in particular. The core of this destructive influence was the violating denial of the need for acknowledgement of these families' terrible traumatic background. This in fact constituted a perpetuating retraumatization, possibly explaining the *endemic* (not epidemic!) appearance of PAWS in Sweden [1].

Twenty-seven children of the 33 in the 2008 study were first-born, studious and sensitive children; 72 % had premorbid histories of both external traumatizing experiences and behavioural disturbances. Fourteen of the 31 *mothers* had a history of psychological problems, and all had been traumatized at the event initiating the flight which for 17 happened <6 months before the arrival in Sweden. The child's personal sensitivity with its direct axis to the mother's failing ability to care and provide security, and her tendency to, at times, subconsciously perpetuate the illness behaviour was a striking clinical observation [1, 9]. The syndrome might in fact rather be conceptualized as a family *psychiatric syndrome* [1, 8]. No refugee children arriving alone have developed the syndrome. A dysfunctional family is one of the main prerequisites for a child to develop the syndrome as was pointed out earlier by Lask and Nunn.

The prevalence of the syndrome in Sweden can be calculated with a certain accuracy. In 2004 about 2 % of the children from all asylum-seeking families developed various degrees of the symptoms, for about half of which progressing into life-threatening conditions [1]. Thus very few children living under the same predicament develop the syndrome which points towards the importance of the

complex interactions of premorbid, precipitating and perpetuating factors.

Biological markers and the diagnosis The present situation in Sweden shows a restoration of basic ethical principles regarding the new refugee children some of which have in fact developed the PAWS. The National Board for Health and Welfare is currently working out guidance for the care for children developing PAWS, and has settled the diagnostic issue. From January 1st, 2014 the syndrome will be identified under the Depression Section of the Swedish ICD-10-SE edition with the specification 32.3A (withdrawal syndrome) and the additional code 65.8. A (problems concerning refugee state and asylum application).

A breakthrough was reported in a study showing that children with PAWS present biological markers identical to what has been demonstrated in patients with long-standing stress and trauma reactions (PTSD) [10]. This study was initiated by our pilot results regarding the lack of daily variations in salivary cortisol levels [1] and will once and for all justify the PAWS to be recognized as a complex PTSD and legitimate its rights to be met with full scientific and medical ethical respect.

Addendum

The Swedish government was seriously criticized in 2006 by professor Paul Hunt, the UN “Special Rapporteur on the right to the highest attainable standard of health”, for not “*offering the same medical care to, on the same basis, as Swedish residents*” with a special reference to “*those children, associated with the asylum process who experience severe withdrawal symptoms*”.

Neither the leadership of the responsible medical speciality, Child and Adolescent psychiatry, nor the National Board for Health and Welfare can claim to have embraced a satisfactorily wide scientific or ethical perspective towards the “*apathetic asylum children*”. The ethical issues

have been concealed by the debate regarding immigration and asylum policies.

Finally, it might be stated that the only general guarantee against politically initiated neglect and abuse of children is the single physician’s loyalty towards the basic ethical rules and the UN child convention.

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