EDITORIAL

Pervasive refusal syndrome and Nauru

Fatima was a happy child who loved school and was a top student. She was 11 years old when she took to her bed, stopped eating and drinking, covered her head with the sheet, stopped washing and started wetting the bed. For months, she would not or could not get out of bed and had to be carried to the toilet. She would not speak to her parents or friends. After over 5 years on Nauru, almost half her life, she had lost control of her destiny, had lost all hope and had lost the will to live. When she was transferred to Australia with her mother, she needed nasogastric tube feeding for a week to maintain hydration and needed a walking aid for 2 months to move around. She gradually began to eat, drink, wash and toilet herself and to socialise. She remained a hospital inpatient for 2 months and is expected to need several more months of intensive outpatient treatment.

Pervasive refusal syndrome is a rare psychiatric condition mainly affecting children aged 7–15 years old, girls three times as often as boys, although the youngest child described is 4 years old.1 The term pervasive refusal was first used by a British child psychiatrist Bryan Lask and his colleagues to describe four girls aged between 9 and 15 with profound and pervasive refusal to eat, drink, walk, talk or care for themselves over a period of several months.2 Sydney clinicians who also saw cases proposed now widely accepted diagnostic criteria (Table 1).3 The condition shares features with but differs from other psychiatric conditions, including depression, anxiety, catatonia, selective mutism and chronic fatigue (Fig. 1). Pervasive refusal syndrome is different from anorexia nervosa, where children are delusional about their weight, but both conditions are potentially life-threatening. Death can result from metabolic derangement due to chronic malnutrition and due to re-feeding syndrome.4,5 Re-feeding syndrome was first described in prisoners of war after World War I. Potentially fatal shifts in fluids and electrolytes can cause encephalopathy and cardiac arrest.4,5

The causes of pervasive refusal syndrome are complex and multifactorial. Although sexual abuse seemed a possible cause in the earliest cases2, it has not been a likely cause in most subsequent cases.1,3 Nunn and Thompson see pervasive refusal syndrome as a profound response to events perceived as uncontrollable, for example, loss of loved ones, any form of extreme abuse, severe parental conflict, migration or frequent moving of home and/or school.3

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Diagnostic criteria for pervasive refusal syndrome</th>
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<tr>
<td>• Clear food refusal and weight loss</td>
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<tr>
<td>• Social withdrawal and school refusal</td>
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<td>• Partial or complete refusal in two or more of: mobilisation, speaking, attention to self-care</td>
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<td>• Active and angry resistance to help or encouragement</td>
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<tr>
<td>• No organic condition or other psychiatric illness</td>
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Fig. 1 Alienation by Syberpat, 2006.

Children with pervasive refusal syndrome have suffered lifelong disabilities, both physical (contractures, scoliosis and osteoporosis) and emotional (entrenched, complex, cumulative post-traumatic stress disorders).1–3,6 So far, no child has been reported to have died from pervasive refusal syndrome, despite the risk of dying from inanition or re-feeding. However, children with anorexia nervosa have died from re-feeding syndrome.7

Eliciting the symptoms of pervasive refusal syndrome does not require psychiatric expertise, although this is required to decide whether the child has another diagnosis, such as major depression, that better explains the symptoms. This makes it a valuable tool to assess children like those on Nauru denied psychiatric expertise but also a diagnosis open to criticism by those only too willing to make accusations of feigned or copycat illness or of over-diagnosis.

The condition became highly politicised in Sweden when over 400 children seeking asylum who had escaped from appalling trauma in their countries of origin developed symptoms similar to pervasive refusal syndrome.6,8,9 They were living in the community, caught in a policy quagmire of administrative paralysis leading to prolonged uncertainty about their refugee status and their future.6 Clinicians debated the overlap and differences between what they termed ‘depressive devitalisation’ and post-traumatic stress disorder.6,9 Eriksson questioned whether the condition was genuine and proposed the parents were
Treatment of pervasive refusal syndrome involves correcting the cause, re-feeding and, for some children, long-term psychological treatment.\textsuperscript{1,6} The first rule of trauma therapy is to remove the child from any ongoing trauma to a place of safety. In the case of children on Nauru, this meant transferring them to the mainland for treatment, together with their family. It is well accepted in child protection that it is impossible to effectively treat children who are being abused if the abuse is allowed to continue. The corollary is that it was not possible to treat children on Nauru with pervasive refusal syndrome while they remained on Nauru.

On 26 February 2018, there were 158 children still on Nauru.\textsuperscript{10} Nine nuclear families were split between Australia and Manus or Nauru.\textsuperscript{10} All the families on Nauru had been there over 5 years. By the end of 2018, all the children and their families had been transferred off Nauru, mostly to Australia and a few to the USA. While this is a huge relief, the Australian government can take no credit, although this has not stopped them trying to do so. Children got off because lawyers started acting for children on Nauru with severe psychiatric problems. The government opposed the children’s transfer. The lawyers asked doctors in Australia to assess the children, which they did by video link using interpreters. The doctors wrote reports. At least 30 of these reports were of children with the symptoms of pervasive refusal syndrome. The lawyers presented the reports to the federal court seeking orders to transfer the children for urgent medical care. Government-appointed lawyers opposed the transfers.

But public sentiment had changed. Up to 2017, 60% of Australian people surveyed felt government policy on asylum seekers was appropriate or not tough enough. In August 2018, World Vision initiated a campaign, #KidsOffNauru, supported by doctors, lawyers and over 30 human rights organisations, which urged the government to get all children off Nauru within 3 months. Members of Parliament were flooded with letters and emails. Whether or not the campaign was the cause, a new survey in October 2018 showed that 79% of the public wanted all children moved off Nauru. After more than 5 years, the government acquiesced but only from political expedience, not because of any sympathy for the children. Both major political parties have relentlessly pursued an immoral policy of offshore detention, designed to deter others from seeking asylum, at the predictable cost of causing adults and children severe mental health problems. We can only hope that getting the children off Nauru and treating them for pervasive refusal syndrome and other psychiatric conditions will be the beginning of the end of this miserable period in Australian history.

Caring for and about children on Nauru with pervasive refusal syndrome has placed paediatricians working in refugee health in an unusual and confronting situation, where the line between advocacy and health care has become blurred in complex and interesting ways. One can only hope that we will never be put in such a situation again, although history tells us not to be too optimistic.

**Acknowledgements**

Fatima (not her real name) and her parents agreed courageously to allow me to tell her story. ‘Courageously’ because many families are scared that if they tell their stories they will be less likely to be granted refugee status and may be returned to Nauru. There are many heroes trying to help children like Fatima, too many to mention by name. They have my heartfelt admiration. I thank Chris Elliot, Stephen Isaacs, Ken Nunn and Helen Young for advice on the content of this editorial.

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**References**