Clinical Child Psychology and Psychiatry (2019) **doi: 10.1177/1359104519846580**

Pervasive Refusal Syndrome in Asylum Seeking Children: Review of the Current Evidence

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Abstract

This study reviews the current evidence in Pervasive Refusal Syndrome (PRS) in asylum seeking children. Refugees can experience a variety of traumas throughout the process of migration. Children can be exposed to multiple traumas such as experienced or witnessed physical or sexual violence, loss and bereavement, parental separation and the threat of persecution and/or kidnapping. The third stage of the migration journey can add further stress; children and families may experience multiple rejections of asylum application effectively living in limbo with the constant threat of deportation. High rates of mental health disorder are well documented in young asylum seekers, particularly depression, anxiety and post-traumatic stress disorder (PTSD). Pervasive refusal syndrome is less frequently described but nonetheless a severe and life-threatening condition affecting young asylum seekers. Traumatisation, cultural factors and hostile asylum processes are specific moderating factors seen in asylum seeking children. Asylum seeking children normally make a full recovery from PRS. This study suggests a link between prolonged asylum processes and hostile foreign policy in developing and maintaining illness; similar cases are now being reported in other countries with hostile foreign policies. These findings are therefore relevant to clinicians and politicians working with this vulnerable group.

Introduction

An unprecedented 65.6 million people around the world have been forced from home. Among them are nearly 22.5 million refugees, over half of whom are under the age of 18 (United Nations High Commissioner for Refugees (UNHCR, 2017). There are an estimated 158,215 child asylum seekers in Europe (UNICEF, 2017).

Refugees may experience traumatic events and significant losses throughout the process of migration and resettlement that can have significant mental health consequences (Refugee Council, 2018). Stressors may occur in any of the three stages of the migration journey. The first occurs at home, in their native countries where many refugees have experienced considerable trauma. They have often been forced to flee their homes because of exposure to conflict and hence witnessed violence, torture, and loss of close family and friends. The journey to a country of refuge is the second stress. It can take months and children are often exposed to more life-threatening dangers, separation from parents and as international immigration controls become more stringent, more children are being placed in the hands of smugglers to ensure their escape. The last stage, in the host country can be a time of additional difficulty as many must prove their asylum claims and children can face uncertainty and fear of deportation back to the crisis they fled from (Hodes & Vostanis, 2018).

The refugee council estimates in the UK up till March 2018, more than 9,824 asylum applications had delays for longer than six months for an initial decision. An 87% increase on March 2016.The total backlog of cases awaiting a decision totalled 22,100. (Refugee Council, 2018)

The mental health of young asylum seekers may be negatively affected by low support and refusal of asylum (Jakobsen, 2017) . Rates of psychopathology can double in cases where there is a prolonged asylum process (Fazel, Reed, Panter-Brick, & Stein, 2012). This research would suggest that these hostile conditions enforced on asylum seekers where children are uncertain and in fear of deportation may cause a rise in psychopathology (Jakobsen, Meyer DeMott, Wentzel-Larsen, & Heir, 2017). High rates of psychiatric disorders in asylum seekers and refugees is well documented; the most prevalent disorders are depression, anxiety disorders and post-traumatic stress disorder (PTSD) (Fazel, Wheeler, & Danesh, 2005;) (Priebe, Giacco, & El-Nagib, 2016). There are other less frequently described disorders that may occur in young asylum seekers and refugees including somatoform disorders and pervasive refusal syndrome (Bodegard, 2005; Hodes and Vostanis, 2018)

Pervasive refusal syndrome (PRS) was first described in a case series including four children in 1991 (Lask et al, 1991). They described a life-threatening disorder with extreme reduction in function; children presented with profound and pervasive refusal to eat, drink, walk, talk, or care for themselves. Characteristically this presentation was combined with a wilful resistance to help. Diagnostic criteria were first proposed in 1997 by Thompson and Nunn and these were later modified to describe refusal in broader categories and not just food refusal and its effect on weight (Thompson SL, 1997) – see table 1.

Table 1. Diagnostic criteria for PRS, Jaspers (2009)

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

Between 2001 and 2006 in Sweden there was a surge in cases of child refugees seeking asylum presenting with a withdrawal syndrome. The first English Language publication describing these Swedish children appeared in 2005, used the term Depressive Devitalisation (DD), thought to be part of the same refusal syndrome as PRS (Bodegard, 2005). No other cases have been documented in Europe(Jaspers T, 2009). There have been similar presentations in Australia more recently, on the offshore refugee processing island of Nauru where at least 30 children are thought to be suffering with 'traumatic withdrawal syndrome' (BBC News, 2018). In recent years there has not been to our knowledge a synthesis of this disparate literature.

Aims of study

This study reports a systematic review of reports of pervasive refusal syndrome (PRS) and similar disorders such as DD in asylum-seeker children. The aim of this study is to describe the clinical picture seen in PRS in asylum seeking and refugee children and to look at possible risk and protective factors paying attention to the experiences of children as they seek asylum. This review will also examine the management of PRS in asylum seeker children both from a clinical perspective and also the role of the asylum process.

Methods

Search strategy

The search was divided into 3 main areas, to include; 'child*', 'Pervasive Refusal Syndrome' and 'Asylum-Seeker'. These were used as the main search terms for the initial search in three databases on 5th December 2017 and repeated 19th April 2018 to ensure no new data had been added. The string of search terms included: Pervasive refusal syndrome in child asylum seekers. Other search terms in place of 'Pervasive Refusal Syndrome' used included: 'Depressive Devitalization', 'Somatisation', 'Withdrawal', 'Giving up', 'Apathy' and 'Resignation Syndrome'.

- Ovid EMBASE (Embase Classic + Embase 1947–2017 December 4th)
- Ovid MEDLINE (in-process and other non-indexed citations and Ovid MEDLINE 1946 to Present)
- Ovid PsycINFO (1806 to December 4th 2017)

The reference list of all identified papers and review papers were searched for additional papers. Authors were also contacted for to ensure no pertinent studies were missed and also to include any current research. All titles and abstracts were screened. Relevant full text papers were obtained where possible. Where doubts arose regarding study inclusion, the first and second author met and came to a decision based on inclusion criteria.

Inclusion and exclusion criteria

Only papers in English were sought. The review included published observational studies; case series and case reports of asylum seeker children under the age of 18 years, who develop symptoms of PRS. Papers looking at Depressive Devitalization, Pervasive Arousal Withdrawal Syndrome and Resignation Syndrome were also screened. Papers were included if new data was published. Cases had to be children seeking asylum or having gone through the asylum process during investigation. Studies were eligible if they examined the demographic features of patients, the clinical presentation of PRS in this group and the treatment provided.

Studies were excluded if the studies main focus was not PRS or other synonymous conditions. Studies on Post-Traumatic Stress Disorder were excluded.

Selection of studies

Searches were de-duplicated electronically via Ovid. All abstracts were screened, and due to the low volume of research in this field authors were also contacted for any pending research. Full text articles were sought where possible and read in full to screen inclusion criteria, looking at the three categories: Appropriate sample, assessment of clinical presentation and description of management.

Data extraction

Data was extracted and tabulated. Information regarding study type, sample characteristics, aetiology, treatment and management and patient journey was extracted.

Results

The database search returned 195 articles. After screening other sources generated by contacting lead authors and grey literature 4 publications were included in the results, see figure 1.

Migration background and aetiology

Reported cases were a mix of boys and girls, with slight female predominance. The youngest case was seven years old, the oldest nineteen and the average age was twelve.

All of Bodegard's (2005a, 2005b) reported cases had fled from Central Asia or the Former Soviet Republic. One study reported asylum seekers fleeing Former Soviet Republics belonging to a political and/or ethnic minority. (Forsland & Johansson, 2013). Arronson (2009) studied cases from Central Asia and six Caucasus. All the cases seen in this review were of children settling in Sweden. See Table. A

Almost all the children across the studies had experienced traumatic events. 21 out of 29 of Arronson's (2009) children had traumatic experiences, according to DSM-IV criteria and 20 had suffered separation or loss of close relatives. Table.2 lists the range of traumas experienced across the cases.

Table.2: Range of Trauma.

- Witnessing sexual violence
- Threat of persecution and/or threat of kidnapping
- Harassment
- Lack of protection
- Direct physical threats
- Acts of sexual/physical violence, killing, cruelty
- Intimidation
- 2 cases witnessed pets killed and
- Witnessed property being destroyed.

Where it was assessed, it was a common factor for families to have experienced rejection of their asylum application. One family experienced seven rejections of their asylum application (Forsland & Johansson, 2013). Bodegard (2005a) reported half of families experiencing refusals and being given deportation orders before development of symptoms, the other half were under initial evaluation when symptoms arose.

Previous psychiatric history was seen in 13 of the 39. Parental mental health difficulties were also seen in 25/39 of the cases. Mental health history in the child or parent was not reported in 23 cases.

Table 3. Systematic review of studies on Pervasive Refusal Syndrome in asylum-seeker children: Aetiological factors

Reference	Country of study	No. cases	*Age (years)*	*Sex*	*Country of origin*	*Country of residence*	*Asylum status*	*Premorbid Personality: high achiever, conscientious*	*Previous child psychiatric problems*	*Enmeshed mother-child relationship*	*Traumatic events*	*Parental mental health*	*Permanent right to remain No. rejections*
Forslund and Johansson (2013)	Sweden	5	*7-17(13.6)*	*3 girls 2 boys*	*Former Soviet Republics*	*Sweden*	*5/5*	*3/5*	*2/5*	*Not reported*	*5/5 "psychosocial/witnessing sexual violence/being beaten"*	*4/5*	*1,1,3,4,7*
Bodegard (2005a)	Sweden	23	*Not reported*	*Not reporter*	*Central Asia, Former Soviet Republic*	*Sweden*	*23/23*	*Not reported*	*Not reported*	*Not reported*	*23/23- severe physical violence and/or killing, sexual abuse, persecution and/or threat of kidnapping*	*16/23*	*50% experienced refusals and been given deportation orders before development of symptoms. Other 50% under initial evaluation*
Bodegard (2005b)	Sweden	5	*7-10(8.4)*	*3 girls 2 boys*	*Former Soviet Republic*	*Sweden*	*5/5*	*Not reported*	*3/5*	*Not reported*	*5/5 " harassment, lack of protection, persecution, direct physical threats, acts of sexual/physical violence, killing, cruelty, intimidation, kidnapping. 2 cases witnessed pets killed and property destroyed"*	*5/5*	*5/5; numbers not reported*
Aronsson (2009)	Sweden	29	*7-19 mean age 14.4*	*17 girls 12 boys*	*Central Asia, 6 Caucasus*	*Sweden*	*29/29*	*Not reported*	*8/29*	*Not reported*	*21/29 "21 of the children had traumatic experiences, according to DSM-IV criteria and 20 had suffered separation or loss of close relatives."*	*Not reported*	*Not reported*

Clinical Presentation

Onset is typically gradual with a prodromal presentation of a 'variety of psychiatric disorders' and admission reasons such as 'apathy', 'giving-up syndrome' and 'refusal to eat and speak'. Closer to admission, reduction in function is mostly rapid (Garmezy, 1983); (Forsland & Johansson, 2013). Almost all the cases seen presented in a similar way to previous research on PRS (Bodegard, 2005a). Most papers described all of Jasper's criteria, with refusal to eat, mobilisation, speech and attention to personal care; incontinence was common. Forslund & Johansson described a variable pattern of refusal during inpatient stays, with combinations of passive and active refusal supporting previous research; arguing that refusal in PRS is a continuum ranging from active refusal to passive refusal(Thompson SL, 1997). In one paper, seven cases could be fed by parents, but no description of any refusal was made (Aronsson 2009). Neurological symptoms were described in three papers, ranging from subtle signs of difference in muscle tonus to more acute spasm and flaccid paralysis. In Bodegard's (2005a) report of 23 cases, he also described secondary symptoms such as tachycardia, pyrexia, weight gain, oedema, profuse sweating, reactivation of latent viral infections, skin ulcers and muscular atrophy.

Suicidal ideation or attempts were also commonly seen across the cases (17 out of 39); it was not reported in one study (23 cases). In two cases 'suicide attempt' was noted as the reason for admission to inpatient services. See Table.4

Table 4. Systematic review of studies on Pervasive Refusal Syndrome in asylum-seeker children: Clinical presentation

Reference	**Clear food refusal and weight loss**	***Partial or complete refusal to mobilise***	***Partial or complete refusal to speak***	**Social withdrawal and school refusal**	***Partial or complete refusal to attention to self-care***	***Active and angry resistance to acts of help and encouragement***	***Comorbid conditions accounting for presentation***	***Neurological symptom/physical symptoms***	***Suicidal ideation/attempts***	***Hospitalisation required?***
Forslund and Johansson (2013)	5/5	5/5	*5/5*	*5/5*	*5/5*	*5/5*	*N*	*1/5- difference in tonus*	*2/5*	*5/5*
Bodegard (2005a)	23/23	23/23	*23/23*	*23/23*	*23/23*	*23/23*	*N*	*Tachycardia, pyrexia, weight gain, oedema, profuse sweating, latent viral infection, skin ulcers, muscular atrophy*	*Not reported*	*23/23*
Bodegard (2005b)	5/5	5/5	*5/5*	*5/5*	*5/5*	*5/5*	*N*	*Flaccid paresis*	*3/5*	*5/5*
Aronsson (2009)	22/29	29/29	*29/29*	*29/29*	*29/29*	*Not reported*	*N*	*6 children with neurological signs of spasm, 10 children had anaemia*	*12/29*	*0/29*

Physical Investigations and Disorders

One study reported 10 out of 23 cases had iron deficiency anaemia which was corrected with supplementation and adequate nutritional intake (Aronsson 2009). Two papers completed toxicology screens due to suspicions that the children may have been drugged, and where reported, no cases of sedative or other compounds were implicated. There is no evidence to support accusations that these cases are malingerers or the children have been drugged by their parents to improve chances of asylum. Radiological investigation included Computed Tomography scanning (CT) in 39 out of 62 cases; 1 MRI was completed (Aronsson 2009). EEG was also completed in most cases. After investigation, none of the papers found evidence of physical health disorder that could account for the children's presentation.

Management

33 out of 62 cases required treatment as an inpatient. The one paper by Aronsson (2009) where children were treated at non-inpatient settings, explained that the study was carried out in the context of a multi-disciplinary treatment programme with intensive input from paediatricians, medical homecare team and a mobile child and adolescent psychiatry team. Care was provided at a child psychiatric day facility and at home with visits 2-4 weekly.

Where reported, a multidisciplinary approach was required, with child psychiatry, paediatric, nursing and physiotherapy teams being involved (Forslund and Johansson, 2013; Aronsson, 2009). An interpreter was also mentioned in one paper, noting 'linguistic misunderstandings' which were resolved easily later (Forslund & Johansson, 2013).

Rating scales and questionnaires were completed in for 39 out of 62 cases. In one study the mean GAF score was 72; mean MADRS-s score was 7.8; mean PCL-C 28. No children met ICD-10 criteria for depression and no cases had PTSD (Forsland & Johansson, 2013). Bodegard (2005b) noted C-GAS scores of <10 in all 5 of his cases, and reported this combination with 'parental failure to provide adequate care' necessitated inpatient care. Aronsson (2009) devised their own functional assessment tool enabling 'a systematic assessment of an individual child's psychiatric, activities of daily living (ADL) functioning, behaviour and somatic symptoms'. They devised their own scoring system, noting that at the lowest level of functioning 'none of the children took action for ADL'.

Almost all cases reported required nasogastric (NG) feeding (55 out of 62 cases). The shortest duration of NG feeding was 4.4 weeks, the longest 98 weeks; this averaged out to 25.8 weeks across the studies where it was reported. One study only reported the duration from admission to end of NG feeding with no information about when NG feeding began, thus extrapolation was difficult. Pharmacological management was noted in 3 out of 4 papers and included; alimemazine, mirtazapine, sertraline and other SSRI's, benzodiazepines and iron supplementation.

Average inpatient stay was reported in two studies with a mean of 4 (2-8.5) months (Forsland & Johansson, 2013); Bodegard, 2005). Some studies reported time from admission to discharge from outpatient care and this gave an insight into duration of treatment to recovery; mean 10.7 (7-29.5) months. On discharge one study reported ICD-10 diagnoses, as PRS is not recognised in any classification system, they included Demoralization and apathy, PTSD, Major Depressive Disorder and Adjustment Disorder.

All studies recognise the asylum process as a significant factor relating to PRS. One study describes the extended asylum-seeking process in their cases and how this was likely to maintain a sense of hopelessness, which is thought to be a risk factor for developing psychiatric illness. The study goes

on to consider the asylum process not only as a risk factor for PRS. However, when right to remain was obtained recovery could begin (Forsland & Johansson, 2013). One study described the permanent residence permit as 'necessary for the restoration of basic life security', going further to suggest it was a condition to successful treatment. The author notes that the permit alone did not in any of the cases cause drastic improvement, and described the protracted treatment that often followed. Aronsson (2009) looked at the range in duration of time from being granted permanent residency to a 'turning point' in rehabilitation (-15 to 16.1 months). This showed that some children started their recovery before being given permanent residency. The paper felt the period of when the study was conducted to be significant, explaining that changes in the Swedish asylum policy meant that all children were granted permanent residency, postulating that the clinical outcomes might not have been so favourable in a different time period.

Table 5. Systematic review of studies on Pervasive Refusal Syndrome in asylum-seeker children: Management

PCL-C PTSD Checklist-Civilian version, MADRS-S Montgomery–Asberg Depression Rating Scale-Self-rating version, C-GAS Children's Global Assessment Scale

Reference	**Inpatient duration (months)**	**Assessment tools**	**Physical examination**	***Investigations***	***Healthcare teams involved***	***Nasogastric feeding, duration(weeks)***	***Pharmacological treatment***	***Outpatient follow-up***	***ICD-10 diagnosis on discharge***	***Time from admission-end of outpatient care (weeks)***	***Permanent right to remain as a management factor***
Forslund and Johansson (2013)	3.2-8.5	GAF, MADRS-S, PCL-C	5/5	Routine bloods tests, toxicology, CT head, ECG EEG	*Psychiatry, paediatrics, Nursing, physiotherapy*	*10-60(27)*	*Alimemazine, Mirtazapine, Sertraline*	*5/5, 1 case requiring NG feeding at home*	*R45.3, F32.2, F43.1, F43.2*	*28-118*	*Y*
Bodegard (2005a)	Not reported	Not reported	23/23	*'physical investigations'*	*Not reported*	*Not reported; admission to end of NG feed 4-34 wks*	*Not reported*	*Not reported*	*Not reported*	*Not reported*	*Y*
Bodegard (2005b)	2-4	C-GAS	5/5	*CT head, EEG, Routine blood tests, urine specimens*	*Not reported*	*5-15(8)*	*SSRI, Benzodiazepines, Alimemazine*	*5/5*	*Not reported*	*Longest 6 months after discharge*	*Y*
Aronsson (2009)	0	Study devised tool: functional assessment	29/29	*ECG, EE, blood tests, urine specimens, toxicology, CT, MRI*	*Psychiatry, paediatrics, social care, immigration, school*	*22/29* *4.4-98 (42.4)*	*Fe supplements*	*NA*	*Not reported*	*NA*	*y*

Discussion

This review describes a rare life-threatening condition that can present in asylum seeking children. High levels of trauma experienced in home countries and in transit to host countries are specific risk factors that are not seen in non-migrant children with PRS or withdrawal. Prolonged asylum processing or rejection of asylum applications can lead to fear of deportation, further traumatising these children. A hostile asylum process may be a risk factor for developing the condition as well as moderating outcomes. Children often require inpatient admission with intensive multidisciplinary intervention and forced feeding. Children ultimately recover, but this can be protracted and full recovery can take years.

Nomenclature and Phenomenology

Since Lask and colleagues described PRS in 1991, there have been a number of different conceptualisations and terminologies for children presenting with withdrawal and pervasive loss of function. Originally PRS was thought to be a form of post-traumatic stress disorder based on the possibility of sexual abuse as the trauma (Jans T, 2011). The cognitive theory of learned helplessness and hopelessness was applied to PRS by Nunn and Thompson, proposing a triad of separation anxiety, social withdrawal and depression arose from the sense that future events were uncontrollable and attempts of escape were futile. Children may have experienced severe traumas such as losing loved ones, abuse and severe parental conflict; experiences that were perceived as out of their control.

Bodegard described Depressive Devitalisation (DD) a life-threatening loss of function in five refugee children (Bodegard, 2005; Lask, Britten, Kroll, Magagna, & Tranter, 1991). There is a strong emphasis on the traumatic experiences of children with DD, not normally seen in PRS. DD and PRS are thought to be sub-groups of the same refusal syndrome. PRS is thought to present with more active refusal, while DD refusal patterns are more passive. There is however no clarity on the definition of passive and active refusal and also how these are modified by the stage of the illness and may be affected by independent factors such as individual and parenting factors such as feeding practices. Another distinguishing feature of DD is “flaccid paralysis and generalised sensory loss” which is not seen in PRS. (Bodegard G. , 2005).

In 2014 Nunn and colleagues sought to re-conceptualise PRS; new term “Pervasive Arousal Withdrawal Syndrome” was suggested where there is a breakdown in the normal relationship between the sympathetic and parasympathetic nervous systems, both in a state of hyperarousal effectively in a “deadlock”. This is thought to require a high input of energy resulting in “numbness, apathy, perplexity, withdrawal and fatigue of exhaustion”. (Kenneth P. Nunn, 2014).

The most recent term ‘Resignation Syndrome’ was recognised by the Swedish National Board of Health and Welfare for epidemiological reasons. Resignation Syndrome is classified among the depressive disorders and thought to offer a pragmatic solution to the phenomenological controversy. Diagnostic criteria are yet to be determined. (Sallin K, 2016).

There are clear similarities in clinical presentation between the earlier descriptions of children with PRS and the asylum seeking children with DD or resignation syndrome. (Sallin K, 2016; Lask et al., 1991). Differences in demography may be seen; the average age of onset in asylum seeking children was slightly older at 12 years compared to 10.5 years when non-asylum seeking children are taken into consideration. This could demonstrate the age at which families decide it is safe for their children to flee their homeland and seek asylum or perhaps the age at which children assume responsibility and awareness of the implications of the asylum process and the threat of deportation. The female predominance is less apparent in the asylum seeking population; PRS most often affects girls (75%). The similar gender distribution could be explained by the extreme traumatic conditions that are invariably experienced by the refugee population; any effects of hypersensitivities in girls are likely to be superseded by the severity of the stressors (Jaspers T, 2009).

Possible individual risk factors for PRS in asylum seeking children

Trauma is likely to be an important risk factor in developing PRS. (Thompson SL, 1997). Almost all cases across the studies experienced range of trauma, these are often experienced in the first and second stages of the migrant journey and present as specific risk factors for asylum seeker children. A premorbid high-achieving, perfectionist, conscientious personality seems to play an important role in the aetiology of PRS generally, as can a psychiatric

history of parents or child. In our research involving asylum seeking children, pre-morbid personality was only recoded in one study (positive in 3/5 cases) and thus comparisons cannot be made. Where reported, 13/39 children had previous psychiatric conditions and 25/33 of parents had mental health issues; we can say that previous mental health in asylum seeking children and their parents are risk factors for the development of PRS consistent with cases of PRS in non-asylum seeking children.

Asylum-seeking process

There is a strong indication from the literature that the asylum process is a risk factor and moderating factor for PRS among asylum-seeking children. When a residence permit is granted, children often start to recover albeit sometimes very gradually. Recovery time after permanent residency is granted varies from days to months; most recover within a few months. In one study all cases received permanent residency due a temporary amnesty in 2016 for refugees in Sweden, cases recovered and the author proposes that the clinical courses could have been 'less favourable' in a different time period. The policy change was thought to contribute to the subsequent decrease in new cases and indicates the potential effects of foreign policy on the incidence of PRS (16 cases in 2016 compared to 188 in 2015 (Hacking, 2010) (Sallin K, 2016).

Prolonged asylum processing is linked to the theoretical conceptualisation of learned helplessness. (Nunn KP, 1996). Bodegard describes a 'fight for rights' that degrades self-esteem and 'a deprivation of normal ego-strengthening activities'. Asylum seeking families are unable to work or make a living, effectively in limbo this can drain and devitalise the children and families leading to a sense of learned helplessness. Forslund & Johansson further proposes the explanatory mechanism; trauma experienced by children and their families in the first and second stage of the asylum seeker journey coupled with the stressful asylum process are deemed to be experienced as recurrent 'uncontrollable events' which is the underpinning mechanism described in previous studies on PRS(Aronsson, 2009). These finding are consistent with previous research in this field; it is known that a prolonged asylum process is a risk factor for psychiatric illness (Laban CJ, 2004). A 2½ year follow-up study of unaccompanied minors seeking asylum in Norway found that mental health trajectory was adversely affected by low levels of support often in inappropriate adult settings (Jakobsen, 2017). Refusal of asylum was linked to high levels of psychological distress(K Robjant, 2009).

Treatment

PRS in asylum seeking children often presents with severe levels of withdrawal with marked reduction in function often requiring NG feeding necessitating inpatient management in a child psychiatric hospital with general paediatric input. A multidisciplinary team is needed with an emphasis on a slow and patient approach as illness is often protracted. It is important to involve the family in treatment to reduce family anxiety keeping in mind the psychodynamic processes that may be at play. (Thompson SL, 1997) (Bodegard G. , 2005). There is little evidence for the use of medication in these cases; unless being used to treat co-morbid disorders such as depression with anti-depressant medication. Patients often began to improve after indefinite leave to remain was granted suggesting this as an important consideration in their management. (Forsland & Johansson, 2013)

Occurrence in Sweden

Sweden in the early 21st century had seen the increasing number of cases of PRS in asylum seeking children, the first reported in 2001; 16 new cases in 2002, 65 more in 2003; 182 more in 2004; and 188 in 2005. Over 400 cases were estimated to exist in Sweden in 2005(Jakobsen M, 2017). Of the 4567 asylum application of 0-17 year old children in 2004, 2.8% were diagnosed (Hacking, 2010). The BBC reports that the Swedish national board of health have seen a decline in the number of cases quoting 169 new cases between 2015-2016 (http://www.bbc.co.uk/news/magazine-41748485, 2017). Despite the high number of cases reported, there have only been a small number of research level published studies. There are a large number of articles reporting cases in the general media and these are largely in the Swedish language. Statistics on prevalence come from the Swedish Government policy papers and these are often quoted in reviews on this subject by local authors and access to this material outside of Sweden has been difficult. In September 2004 after intense media exposure and national sense of scandal, the Swedish Government appointed a national coordinator to open an official enquiry into the high

number of cases of asylum-seeking children with severe withdrawal behaviour. It was thought that this phenomenon was unique to Sweden and no cases have been reported outside of Sweden (Hacking, 2010).

Research in Pervasive Refusal Syndrome is scant, and further still when associated with asylum seeking children. Many cases discussed were from Sweden at a time when asylum seeking children were not offered the same level of care as Swedish residents and this was a key criticism in 2016 by the UN ‘‘Special Rapporteur on the right to the highest attainable standard of health’’("http://www.bbc.co.uk/news/magazine-41748485," 2017). This review did not find any report of cases outside of Sweden and this is consistent with other reviews in this field (Bodegard G. , 2014). Efforts to understand the regional distribution and prevalence have been attempted and there is no clear consensus. It has been described as a ‘culture-bound’ phenomenon but we should be mindful that this does not disqualify other potential pathogenic factors such as individual traits, type and severity of traumatisation and levels of support from host countries. Not all asylum seeking children facing similar stressors develop the illness and there is a need for more research looking at aetiology with clinical details of reported cases. However the recent harshness towards asylum seeking children has seen reports of what could be PRS in asylum seeking children detained in Nauru, administered by the Australian government (Harrison, 2018)

Strengths and Limitations

This study is a systematic review of PRS and other similar disorders such as DD. It provides a summary of aetiology, clinical presentation and management of reported cases of PRS in asylum seeking children. Previous reviews have included a case mix including children not seeking asylum. The search for papers was robust to include contacting authors of current research.

This review is limited by the number of papers on this subject; the low sample size and the variability in measures (and low use of standardised instruments). The general low quality made use of an instrument to assess study quality impractical. Not all studies were accessible due to being written in Swedish and some articles were published in non-medical journals thus there may be unaccounted cases. Much of the data looked at was summarised and individual data was often not available, making direct comparisons difficult.

Another limitation is that all cases were of children fleeing to Sweden and this will have cultural and specific factors relating to foreign policy which may affect results and therefore findings are not necessarily generalisable. Two papers were from the same author and it is unclear if all the cases were different.

Conclusion:

Pervasive refusal syndrome is a life-threatening condition that is reported in asylum seeking children. Cases are relatively rare and can present in a similar way to non-asylum seeking children. Traumatisation, cultural factors and hostile asylum processes are specific moderating factors seen in asylum seeking children. This review is descriptive in nature and emphasises the need for further research to examine aetiology and its epidemiology in this group. Asylum seeking children normally make a full recovery from PRS although cases can be long and protracted. This review suggests a link between a prolonged asylum process and hostile foreign policy in the development and maintenance illness; similar cases are now being reported in other countries with hostile foreign policies. These findings are therefore relevant to clinicians and politicians working with this vulnerable group.

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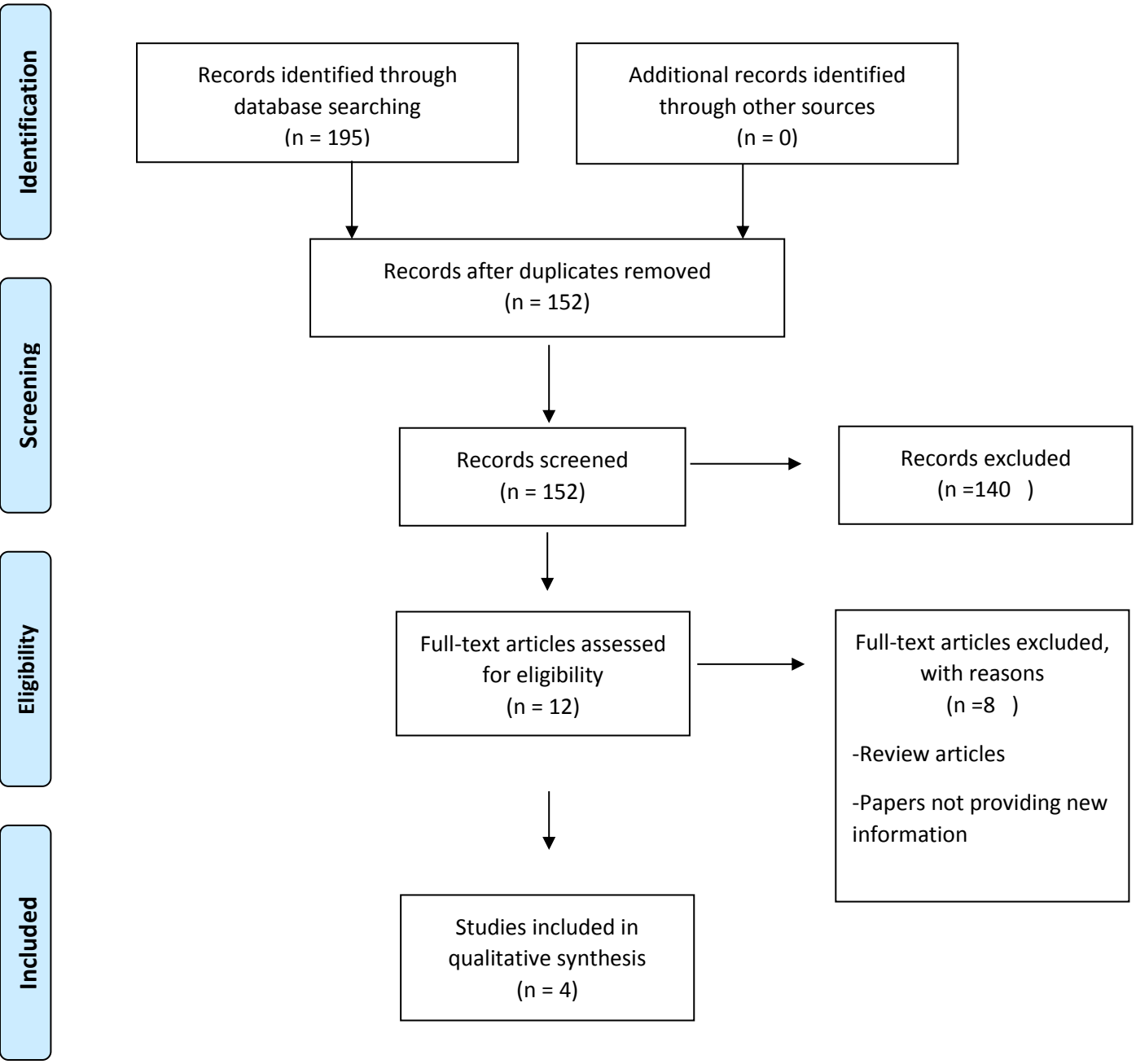
Figure. 1


Identification
Screening
Eligibility
Included
Records identified through database searching (n = 195)
Additional records identified through other sources (n = 0)
Records after duplicates removed (n = 152)
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Records excluded (n =140)
Full-text articles assessed for eligibility (n = 12)
Full-text articles excluded, with reasons (n =8)
-Review articles
-Papers not providing new information
Studies included in qualitative synthesis (n = 4)