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**Literature search results**

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**Search details**

Pervasive refusal syndrome

**Resources searched**

NICE Evidence; TRIP Database; Cochrane Library; CINAHL; EMBASE; MEDLINE; PsychINFO; Google Scholar

**Database search terms:** "pervasive refusal" adj2 syndrome"; "pervasive arousal withdrawal syndrome"

**Evidence / Google Scholar search string(s):** ("pervasive refusal syndrome" OR "pervasive arousal withdrawal synndrome" OR "pervasive refusal") adolescent

**Summary**

There is some research available, although a lot is now quite dated, but you may find it useful for background.

**Guidelines and Policy**

None found.
Evidence Reviews

None found.

Published Research – Databases

1. Pervasive refusal syndrome (PRS) 21 years on: A re-conceptualisation and a renaming.

Author(s) Nunn, Kenneth P., Lask, Bryan, Owen, Isabel

Citation: European Child & Adolescent Psychiatry, Mar 2014, vol. 23, no. 3, p. 163-172, 1018-8827 (Mar 2014)

Publication Date: March 2014

Abstract: Twenty-one years ago, Lask and colleagues first described pervasive refusal syndrome (PRS) as a child’s “dramatic social withdrawal and determined refusal to walk, talk, eat, drink, or care for themselves in any way for several months” in the absence of an organic explanation. PRS has been conceptualised in a variety of ways since then. These have included a form of post-traumatic stress disorder, learnt helplessness, ‘lethal mothering’, loss of the internal parent, apathy or the ‘giving-up’ syndrome, depressive devitalisation, primitive ‘freeze’, severe loss of activities of daily living and ‘manipulative’ illness, meaning the possibility that the children have been drugged to increase chances of asylum in asylum-seeking families. Others have insisted that PRS is simply depression, conversion disorder, catatonia or a factitious condition. This paper reviews these conceptualisations, explores some of the central complexities around PRS and proposes a neurobiological explanatory model, based upon autonomic system hyper-arousal. It touches upon the clinical implications and suggests a new name for the condition reflecting what we believe to be a more sophisticated understanding of the disorder than was available when it was first described. (PsycINFO Database Record (c) 2014 APA, all rights reserved)(journal abstract)

Source: PsycINFO

Available in fulltext from European Child & Adolescent Psychiatry at EBSCOhost
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Available in fulltext from European Child & Adolescent Psychiatry at EBSCOhost
Available in fulltext at European Child & Adolescent Psychiatry; Collection notes: Academic-License. Please when asked to pick an institution please pick NHS. Please also note access is from 1997 to date only.

Available in fulltext from European Child & Adolescent Psychiatry at EBSCOhost

2. Pervasive refusal syndrome among inpatient asylum-seeking children and adolescents: A follow-up study

Author(s) Forslund C.-M., Johansson B.A.

Citation: European Child and Adolescent Psychiatry, April 2013, vol./is. 22/4(251-258), 1018-8827;1435-165X (April 2013)

Publication Date: April 2013

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 10 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: Three 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, Malmo, 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 5 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. © 2012 Springer-Verlag Berlin Heidelberg.

Source: EMBASE
Available in fulltext from European Child & Adolescent Psychiatry at EBSCOhost
Available in fulltext from European Child and Adolescent Psychiatry at ProQuest
Available in fulltext from European Child & Adolescent Psychiatry at EBSCOhost
Available in fulltext at European Child & Adolescent Psychiatry: Collection notes: Academic-License. Please when asked to pick an institution please pick NHS. Please also note access is from 1997 to date only.
Available in fulltext from European Child & Adolescent Psychiatry at EBSCOhost

3. Pervasive refusal syndrome.

Author(s) Wright, Barry, Beverley, David

Citation: Clinical Child Psychology and Psychiatry, Apr 2012, vol. 17, no. 2, p. 221-228, 1359-1045 (Apr 2012)

Publication Date: April 2012

Abstract: We report here on a case of severe pervasive refusal syndrome. This is of interest for three reasons. Firstly, most reported cases are adolescent girls; our case is regarding an adolescent boy. Secondly, he was successfully treated at home and thirdly, the serology showed an apparent infective pre-cursor to the illness with evidence of possible autoimmune serology. A 14-year old boy deteriorated from a picture where diagnosed CFS/ME developed into Pervasive Refusal Syndrome. This included the inability to move or speak, with closed eyes, multiple tics, facial grimacing, heightened sensitivity to noise (hyperacusis) and touch (hyperaesthesia), and inability or unwillingness to eat anything except small amounts of sloppy food. Successful rehabilitation is reported. Finally the issue of nomenclature is discussed, raising the question whether Pervasive Refusal Syndrome would be better renamed in a way that does not imply that the condition is always volitional and oppositional, as this can distract focus away from an alliance between family and clinicians. (PsycINFO Database Record (c) 2012 APA, all rights reserved)(journal abstract)

Source: PsycINFO
Available in print at Grantham Hospital Staff Library

4. "Compelled to die": Psychotherapy with a girl who does not talk, walk, or eat.

Author(s) Magagna, Jeanne


Publication Date: January 2012

Abstract: This reprinted article originally appeared in Exploring eating disorders in adolescents: The generosity of acceptance, Volume II, 2004, 107-138. (The following abstract of the original article appeared in record 2004-15009-005.) Emaciated, eyes closed to every object or person, she lay on the hospital bed. She refused food and drink and seemed not to notice urine trickling out of her. With her straight dark hair and smooth
oval Modigliani face, she looked like a porcelain doll. She was motionless throughout the
day and night. When after some time she began to respond, she treated any nurse's touch
or word like a mosquito creating a stinging irritation. She looked as though the umbilical
cord that held her in life had been broken. There seemed to be no emotional point to her
existence. I shall now describe how this child suffered from what the Mildred Creak Eating
Disorders Team at Great Ormond Street Hospital have described as "pervasive refusal
syndrome", and how she was helped within a pediatric inpatient setting to regain hope to
live. Pervasive refusal syndrome is an extreme example of the profound helplessness and
hopelessness that underlies many severe eating disorders. It can mask various
pathologies, including psychotic depression, anorexia nervosa, and related problems. The
treatment illustrated involves work in the transference and use of the countertransference.
Attention is paid to the total contextual milieu, and to the mechanisms of splitting and
projection, which may involve the therapist herself, staff, child, and family. The therapeutic
work involves family therapy, parental counselling, and cooperation of the teaching staff,
pediatric nursing staff, and the mother as therapeutic agents working alongside the
individual therapist. The chapter also illustrates the powerful impact on the environment of
a profoundly ill girl in a near catatonic state, depressive stupor, or a profound Spitzian
"conservation withdrawal reaction". (PsycINFO Database Record (c) 2013 APA, all rights
reserved)(create)

Source: PsycINFO

5. Inpatient care of a child who does not walk, talk, or eat.

Author(s) Guiney, Jo

Citation: The silent child: Communication without words., Jan 2012, (2012), p. 139-504
(2012)

Publication Date: January 2012

Abstract: When encountering a child who has withdrawn from the world, we naturally feel
the urge to help, to do anything within our means to coax the child out of their entrapment,
their shell. When attempts to do this are met with angry defiance, it can be quite a shock.
The child's withdrawal from everyone and everything in life challenges us on many levels: It
can frustrate, it can eat away at empathy, it can stir up wishes to retaliate with neglect or
anger. Caring for a child whose capabilities are only utilised in order to fend off anything
that might help him reconnect with the world can be baffling, disorientating, and deeply
challenging. It can expose in sharp relief the usual nursing assumption about helping: that
someone wants to be helped. This chapter is based on my experiences of working as a
therapeutic careworker and keyworker to children who were in various states of withdrawal
from life. All of the children resided in a child and adolescent inpatient unit specialising in
the treatment of eating disorders. Refusal forms a fundamental component of the
presentation of eating disorders, this much is clear. However, this chapter will be based on
experiences of working with non-speaking children who profoundly retreat from life when
feeling hopeless and helpless. This syndrome has been labeled as pervasive refusal
syndrome (Lask et al.) but actually it is basically a pervasive retreat from life or a pervasive
regression. The withdrawal from life spreads across multiple domains of eating, drinking,
walking, talking, and self-care. The style of therapeutic work within this particular treatment
milieu is explored in relation to a pervasively regressing child, Michael. In writing about my
experiences with Michael, a particular approach to treatment will be outlined, which is
based on an acceptance of the child's current state of withdrawal from a terrifying world
and the minimising of expectations placed on him over and above non-negotiables, that are
clearly delineated, predictable, and consistent. "Non-negotiables" refers to those aspects of
care or participation in treatment that are held as an expectation of the child, in spite of the
child's wish to completely withdraw from life. Such an approach might be utilised in
approaching the care of silent children in widely differing states of retreat from life
throughout their recovery. This is linked with the amount of terror and helplessness that the
child experiences. As simple as it may at first sound, such an approach can go against the
grain of the usual ways of caring for unwell children and cause a great deal of tension and
anxiety in the multidisciplinary clinical team, and wider inpatient group. It is, however, an
approach to a non-speaking, pervasively retreating child, Michael, that ensures physical
safety while at the same time granting the space required to contemplate change. I hope to
capture two important aspects of working with a child who pervasively retreats. The first is
to give a sense of the practical tasks involved in giving structure to the provision of
sensitive care. The second is to provide an account of the subtle interactions that are the
delicate fabric of such a structure. (PsycINFO Database Record (c) 2013 APA, all rights
reserved)(chapter)

Source: PsycINFO

6. Pervasive refusal syndrome: Three German cases provide further illustration.

Author(s) Jans, Thomas, Ball, Juliane, Preiss, Maike, Haberhausen, Michael, Warnke,
Andreas, Renner, Tobias J.

Citation: Zeitschrift für Kinder- und Jugendpsychiatrie und Psychotherapie, Sep 2011, vol.
39, no. 5, p. 351-359, 0301-6811 (Sep 2011)

Publication Date: September 2011

Abstract: Pervasive refusal syndrome (PRS) has been proposed as a new diagnostic
entity among child and adolescent psychiatric disorders. It is characterized by a cluster of
life-threatening symptoms including refusal of food intake, decreased or complete lack of
mobilization, and lack of communication as well as a retreat from normal life activities.
Active refusal to accept help as well as neglect of personal care have been core features of
PRS in the limited number of cases reported in the last decade. There have, however, been
cases with predominantly passive resistance, indicating the possibility that there may be a
continuum from active refusal to passive resistance within PRS. Postulating this continuum
allows for the integration of “depressive devitalization”—a refusal syndrome mainly
characterized by passive resistance—into the concept of PRS. Here, three case vignettes
of adolescent patients with PRS are presented. The patients’ symptomatology can be
allocated on this continuum of active refusal to passive resistance supporting the
usefulness of such a continuum in comparing various clinical presentations of PRS. PRS
and dissociative disorders are compared in greater detail and contrasted within this
discussion of differential diagnoses at the poles of such a continuum. PRS is a useful
diagnosis for cases involving symptoms of predominating refusal and retreat which cannot
satisfactorily be classified by existing diagnostic categories, and which can mostly clearly
be separated from dissociative disorder. (PsycINFO Database Record (c) 2013 APA, all
rights reserved)(journal abstract)

Source: PsycINFO

7. Overview of the eating disorders.

Author(s) Bryant-Waugh, Rachel, Lask, Bryan

35-439 (2007)

Publication Date: January 2007

Abstract: This chapter gives an overview of the main types of eating disorder and eating
disturbance occurring in children aged 8 to 14 years. The group of children with Anorexia
Nervosa (AN) and related presentations is predominantly female, though a constant
number of boys are seen. Children who present with disorders other than AN show a more
even gender balance across this group as a whole, although there are some differences
between the different types of eating disturbance in relation to the relative numbers of boys
and girls. Working definitions are given for the following types of eating disorder and eating
disturbance in this chapter: anorexia nervosa, bulimia nervosa, food avoidance emotional
disorder, selective eating, restrictive eating, food refusal, functional dysphagia and other
phobic conditions, pervasive refusal syndrome, and appetite loss secondary to depression.
An overview of the diagnosis of eating disorders in children is also given, including the most
commonly applied diagnostic criteria of ICD-10 (WHO, 1992) and DSM-IV (American
Psychiatric Association). (PsycINFO Database Record (c) 2012 APA, all rights
reserved)(chapter)

Source: PsycINFO

A number of asylum-seeking children in Sweden have developed a pervasive loss of function associated with profound social withdrawal. The syndrome is called Depressive Devitalization. The aim of this study was to identify possible aetiological factors, outline the similarities between Depressive Devitalization and Pervasive Refusal Syndrome and to explore possible differential diagnoses. The research was based on a literature study. Databases searched included PsychINFO, Medline, Pub med, COCHRANE and PILOTS. Possible aetiological factors identified included: Children having a perfectionist, ambitious and conscientious premorbid personality, psychiatric problems of children and parents, and traumatic events. Symptoms between the two syndromes differed only in pattern of refusal and neurological symptoms. None of the differential diagnoses explored could account for all features. The individual impact of aetiological factors requires further investigation. Children might previously have been diagnosed with a number of differential diagnoses, though none of these accounts for all symptoms seen in the syndromes. Depressive Devitalization and Pervasive Refusal Syndrome are suggested to be subgroups of the same refusal syndrome.

Source: Medline
Available in print at Grantham Hospital Staff Library

9. Pervasive refusal syndrome

Author(s) Lask B.
Citation: Advances in Psychiatric Treatment, March 2004, vol./is. 10/2(153-159), 1355-5146 (March 2004)
Publication Date: March 2004
Abstract: Pervasive refusal syndrome is a severe, pervasive and life-threatening disorder. Most commonly seen in girls between the ages of 8 and 15, although also affecting boys and younger age groups, it is characterised by a profound and pervasive refusal to eat, drink, talk, walk and engage in any form of self-care. A determined resistance to treatment is a striking component of the condition. The causes are unclear, but likely to be complex, multiple and associated with a sense of hopelessness. Treatment needs to be comprehensive and is based on supporting the child in recovering at her own pace, while ensuring physical safety and well-being. The prognosis is good, provided treatment is appropriate, but recovery tends to take a year or more.
Source: EMBASE
Available in print at Grantham Hospital Staff Library

10. "I didn't want to die, but I had to": The pervasive refusal syndrome

Author(s) Magagna, Jeanne
Publication Date: January 2004
Abstract: Emaciated, eyes closed to every object or person, she lay on the hospital bed. She refused food and drink and seemed not to notice urine trickling out of her. With her straight dark hair and smooth oval Modigliani face, she looked like a porcelain doll. She was motionless throughout the day and night. When after some time she began to respond, she treated any nurse's touch or word like a mosquito creating a stinging irritation. She looked as though the umbilical cord that held her in life had been broken. There seemed to be no emotional point to her existence. I shall now describe how this child suffered from what the Mildred Creak Eating Disorders Team at Great Ormond Street Hospital have described as "pervasive refusal syndrome", and how she was helped within a pediatric
inpatient setting to regain hope to live. Pervasive refusal syndrome is an extreme example of the profound helplessness and hopelessness that underlies many severe eating disorders. It can mask various pathologies, including psychotic depression, anorexia nervosa, and related problems. The treatment illustrated involves work in the transference and use of the countertransference. Attention is paid to the total contextual milieu, and to the mechanisms of splitting and projection, which may involve the therapist herself, staff, child, and family. The therapeutic work involves family therapy, parental counselling, and cooperation of the teaching staff, pediatric nursing staff, and the mother as therapeutic agents working alongside the individual therapist. The chapter also illustrates the powerful impact on the environment of a profoundly ill girl in a near catatonic state, depressive stupor, or a profound Spitzian "conservation withdrawal reaction". (PsycINFO Database Record (c) 2012 APA, all rights reserved)(chapter)

Source: PsycINFO

11. Schooling.
Author(s) Tate, Anna
Publication Date: January 2000
Abstract: Argues that the causal factors for childhood onset eating disorder are multiple and inevitably either involve or eventually affect the child's school work. Therefore, school has a key role in multidisciplinary interventions providing it can be harnessed to complement and reinforce treatment aims. The following topics are discussed: eating disorders and school; identifying pupils with eating disorders; professional boundaries; education as part of a multidisciplinary assessment; liaison between the treatment team and the school; the role of teachers in the treatment team; arranging the school meeting; how much school? (part-time school programs); reintegration into school (allocating a buddy, emotional support at school); eating at school; the volume and content of school work; creative activities in the school curriculum; preparing for examinations; dealing with worries; using school activities as an incentive for weight gain; dealing with perfectionism; dealing with social withdrawal; collaborative work in the classroom; pupil self-evaluation and evaluation by peers; the effective use of teaching strategies; working with inpatients (making a record of achievement, pervasive refusal syndrome); and children with intractable eating disorders. (PsycINFO Database Record (c) 2012 APA, all rights reserved)(chapter)

Source: PsycINFO

Author(s) Nunn, Kenneth P., Thompson, Susan L., Moore, Sharon G., English, Margaret, Burke, Elizabeth A., Byrne, Noela
Publication Date: April 1998
Abstract: Discusses pervasive refusal syndrome, which is a condition manifested by a profound and pervasive refusal to eat, drink, walk, talk or care for oneself. The management of pervasive refusal syndrome illustrates the practical application of hope promoting principles in clinical work. It involves a multidisciplinary team approach and a structured yet flexible management plan with a clear rationale employed over months to years. This article details the components of such a plan, including nursing management, physiotherapy, individual and family therapy. Pre-admission expectations, the necessary assessments on admission, and the establishment of management goals are also discussed. The issue of consent is elaborated, emphasizing the problematic role that refusal plays. Steps to ensure the child's survival and optimal development are outlined. Specific problem behaviors in the child and the family are described, and the need for adequate support within the treatment team to deal with these problems is considered. Attitudes that facilitate staff survival of the long haul of treating these children are
described. Despite the difficulties, however, the typically favorable outcome of treatment is reported. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

**Source:** PsycINFO


**Author(s):** Thompson, Susan Lynne, Nunn, Kenneth Patrick

**Citation:** Clinical Child Psychology and Psychiatry, Jan 1997, vol. 2, no. 1, p. 145-165, 1359-1045 (Jan 1997)

**Publication Date:** January 1997

**Abstract:** Presents an Australian sample of seven Pervasive Refusal Syndrome patients (6 females aged 10–15 yrs and 1 male aged 14 yrs) seen over a period of four years at the Royal Alexandra Hospital for Children, Sydney. Criteria for case inclusion are specified. The features of this sample of children are described and the components of treatment program are summarized. Brief outcome is reported. Issues of differential diagnosis are elaborated highlighting the distinctive nature of the syndrome and its relationship to other disorders. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

**Source:** PsycINFO

14. The pervasive refusal syndrome: Learned helplessness and hopelessness.

**Author(s)** Nunn, Kenneth Patrick, Thompson, Susan Lynne

**Citation:** Clinical Child Psychology and Psychiatry, Jan 1996, vol. 1, no. 1, p. 121-132, 1359-1045 (Jan 1996)

**Publication Date:** January 1996

**Abstract:** Presents the case of a 15-year-old girl with Pervasive Refusal Syndrome as an example of learned helplessness. The theory of learned helplessness is traced from its original descriptions to more recent formulations in which the behaviors of helplessness are linked to the loss of hope. The criteria of helplessness and the phenomenology of the Pervasive Refusal Syndrome are compared. The Pervasive Refusal Syndrome is a difficult condition to treat. The learned helplessness/hopelessness formulation provides a helpful theoretical paradigm within which to conceptualize phenomenology, aetiology and treatment. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

**Source:** PsycINFO


**Author(s)** Bryant-Waugh, Rachel, Lask, Bryan

**Citation:** Child Psychology & Psychiatry & Allied Disciplines, Feb 1995, vol. 36, no. 2, p. 191-202, 0021-9630 (Feb 1995)

**Publication Date:** February 1995

**Abstract:** Describes the characteristics of childhood onset anorexia nervosa (AN) and other eating disorders in children aged <15 yrs. The other eating disorders include bulimia nervosa, selective eating, food-avoidance emotional disorder, and pervasive refusal syndrome. A description of the diagnostic criteria, epidemiology and demography, pathogenesis, psychological and familial factors, management, and outcome of childhood onset AN is included. (PsycINFO Database Record (c) 2013 APA, all rights reserved)

**Source:** PsycINFO

Available in fulltext from Journal of Child Psychology & Psychiatry at EBSCOhost

16. Children with pervasive refusal

**Author(s)** Lask B., Britten C., Kroll L., Magagna J., Tranter M.
Four children are described with a potentially life threatening condition manifested by profound and pervasive refusal to eat, drink, walk, talk, or care for themselves in any way over a period of several months. The multiplicity and severity of the symptoms in these children do not fit comfortably into any existing diagnostic category. Long term and highly skilled nursing and psychiatric care is required to help these children to recover. The possible causes of this syndrome are discussed.
Life-threatening loss of function in refugee children: Another expression of pervasive refusal syndrome?
G Bodegård - Clinical Child Psychology and Psychiatry, 2005 - ccp.sagepub.com

... He established a unit in Stockholm for adolescents needing compulsory care thus guaranteeing them ... CONTACT : Göran Bodegård, Child and Adolescent Psychiatric Clinic of Stockholm, Child Psychiatric Ward, Eugenia ... This has been called pervasive refusal syndrome (PRS). ...

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The role of music therapy in the treatment of a girl with pervasive refusal syndrome: exploring approaches to empowerment


Cited by 7 Related articles All 4 versions Cite Save

Follow-up study of four cases of pervasive refusal syndrome.
Guirguis S¹, Reid C, Rao S, Grahame V, Kaplan C.
The term pervasive refusal syndrome was first mentioned in a paper detailing a sample study of four children by Bryan Lask and colleagues in 1991. This article presents a sample of four children diagnosed with Pervasive Refusal Syndrome, three girls and a boy, seen within a specialist NHS inpatient unit in the North East of England, and describes the main features presented. The main focus of the article will be on long-term prognosis and outcome in relation to day to day functioning and activities. Each of the cases has been followed up once at an interval of between 3 and 16 years after discharge, and the outcomes are presented here. Results suggest that two of the young people with PRS made a complete recovery in the long term, that one was impaired by anorexia nervosa at follow-up, and the remaining young person was reluctant to be interviewed, so it is unclear how well she has maintained her initial discharge recovery.

Published Research – Database Search Strategy

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