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Clinical Aspects and Diagnostic Challenges of Ekbom Syndrome: A Narrative Review

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Abstract:

Background: Ekbom syndrome is an uncommon but likely underdiagnosed psychiatric disorder in which patients hold a persistent belief that they are infested with living organisms, most commonly affecting the skin. Due to the predominance of dermatological symptoms, diagnosis is often delayed, as patients initially seek care from non-psychiatric specialists before being referred for psychiatric evaluation. The syndrome may occur in a primary form, without an identifiable underlying condition, or as a secondary manifestation of other disorders, including psychiatric and somatic diseases. Symptom overlap with other conditions further complicates the diagnostic process.

Aim: The aim of this review is to summarize current knowledge on Ekbom syndrome, including its clinical presentation, diagnosis, and treatment, and to compare it with selected case studies illustrating how the disorder presents and is managed in clinical practice.

Material and methods: A literature review was conducted using the PubMed database. Case reports published between 2020 and 2025 were included, along with earlier highly cited studies where relevant.

Results: The findings indicate that diagnosis is frequently delayed due to patients' strong belief in a somatic origin of their symptoms. Diagnostic pathways vary considerably, highlighting the lack of a standardized approach. While most patients fit the typical demographic profile, atypical presentations in terms of age and symptomatology also occur. Treatment, most

commonly involving antipsychotic medications or addressing underlying conditions in secondary cases, is generally effective once the correct diagnosis is established.

Conclusions: Ekbom syndrome remains a diagnostic challenge, particularly for non-psychiatric clinicians. Improving awareness across medical specialties is essential to reduce underdiagnosis and facilitate earlier initiation of appropriate treatment.

Key words: Ekbom syndrome; delusional parasitosis; delusional infestation; psychodermatology; psychiatric disorder

1. Introduction

1.1 Syndrome overview

Ekbom syndrome, also known as delusional parasitosis, psychogenic parasitosis or delusional infestation [11], is an uncommon psychiatric condition classified in the ICD-10 as a persistent delusional disorder [10] and in the DSM-5 as a somatic type of delusional disorder [10, 11]. A characteristic feature of this syndrome is a persistent and firm conviction that the body (most commonly the skin) is infested by parasites, insects, or other living organisms, despite the absence of objective medical evidence [1, 2].

Clinically, this disorder is not limited to delusional conviction but is frequently accompanied by abnormal tactile sensations, such as itching or sensation of organisms crawling on or beneath the skin [3, 15]. Ekbom syndrome may occur as an isolated psychiatric condition or as part of a broader, more complex mental disorder, often significantly impairing daily functioning and social interactions [1].

1.2 Demography and prevalence

Delusional parasitosis is considered a rare condition, although its exact prevalence remains unclear due to limited epidemiological data [4, 9]. Available estimates suggest that it occurs relatively rarely, with a prevalence of around 27.3 per 100,000 [7] although the data vary between sources. The syndrome is most commonly observed in middle age (with an average age of fifty-seven) and shows a clear predominance in women (although among younger patients the prevalence may be equal) [16], often those who are socially isolated or have a lower level of education [1, 3, 4, 7, 12].

1.3 Historical background

The first known clinical descriptions of the disorder date back to the late 1930s, when the Swedish neurologist Karl Axel Ekbom characterized it as a presenile delusion of infestation

and described patients who were firmly convinced that small organisms were living on their skin [1, 9]. Subsequently, the term “delusional parasitosis” was introduced by other authors [1]. However, to this day, the eponym of the original author is still used in the literature [9].

1.4 Clinical presentation

In the clinical picture, a fixed belief of infestation is accompanied by sensory experiences such as itching, pinpricking or the sensation of organisms crawling on or under the skin [1, 3, 14]. Typical of this syndrome is the “specimen sign” (also known as “matchbox sign”) where patients keep skin elements, threads, hair, sand or insects in small boxes as proof of infestation [4, 7, 18]. The source of parasites is usually known to the patient (e.g. it can be furniture, a vehicle) [16]. Patients often scratch their skin and try to remove the perceived organisms. Over time these repeated actions result in skin damage, most commonly affecting areas such as the scalp, face, limbs or genital regions [3].

1.5 Types and Comorbidities

Ekbom syndrome can present in different forms: it is classified as primary when it occurs independently, without being triggered by any underlying illness or condition. It is secondary when it is caused by psychiatric, somatic, or other medical conditions [11]. Based on the literature, primary forms comprise from 40% to approximately 56% of the cases [7, 14]. Psychiatric conditions that may cause Ekbom syndrome include schizophrenia, depression, and bipolar disorder [2, 4]. The syndrome may also co-occur with Capgras syndrome, which involves the false belief that a person important to the individual has been replaced by an identical double [8].

Non-psychiatric comorbidities include neurological disorders (e.g., dementia, multiple sclerosis), metabolic and systemic diseases (e.g., diabetes, anemia), and infections (e.g. HIV, syphilis, tuberculosis). Additionally, side effects of certain medications (e.g. ciprofloxacin, amantadine, steroids) or substance use, particularly stimulants such as cocaine or amphetamines - may contribute to symptom development [1, 11].

Cultural and environmental factors may also play a role in the development of the syndrome, as patients may attribute the perceived infestation to specific surroundings or objects [13].

An additional form of delusional infestation has been described in cases where not only one individual holds the false belief of being infested, but others (usually close relatives) share this conviction. This phenomenon is known as *folie à deux* [4, 11].

1.6 Pathophysiology

The exact pathophysiological mechanisms underlying delusional infestation are still not fully understood. Some hypotheses point to disruptions in dopaminergic pathways, particularly

involving increased dopaminergic activity [1, 10]. Neuroimaging findings also indicate the possible involvement of brain regions such as the striatum (especially the putamen), which plays an important role in the sensory integration and perception. Dysfunction in these neural circuits may contribute to the development of somatic delusions and abnormal tactile sensations [9].

Considering how the condition appears in males and females across age groups - showing similar frequency in patients under 50 and a 3:1 ratio for women after that age - this suggests that hormonal factors may contribute to the development of this syndrome [17].

1.7 Diagnosis

Diagnosing Ekbom syndrome is challenging due to patients' strong conviction that their symptoms have a somatic rather than psychiatric origin [4]. They typically seek help from general practitioners or dermatologists before psychiatric consultation is considered [1, 4, 7]. Seeking help from specialists from other fields, e.g. tropical medicine or microbiology, can also occur [18].

Key diagnostic criteria include a persistent belief of infestation despite contrary evidence [1]. According to some sources, symptoms must persist for at least one month and may be accompanied by hallucinations, most commonly tactile, but sometimes also visual [1, 3]. Another important characteristic is patients' limited insight into their condition, which makes them resistant to the diagnosis and may delay their treatment [1].

1.8 Treatment option

A standardized treatment approach for delusional parasitosis has not been established [1]. When initially misdiagnosed, it tends to be treated with anti-scabietic medications [18]. Once recognized as a psychiatric condition, the management typically includes second-generation antipsychotics such as risperidone, olanzapine or aripiprazole, which are generally preferred due to their safety profile [1, 10]. In cases of treatment resistance, clozapine or electroconvulsive therapy may be considered [4].

Additionally, selective serotonin reuptake inhibitors (SSRIs) may be used when depressive symptoms coexist. All treatment options should be carefully evaluated with regard to potential side effects, especially in older patients or those with comorbid conditions [10].

Beyond pharmacological interventions, the patient-doctor relationship plays a crucial role in successful treatment. Patients may present with mistrust, which can lead to poor adherence, seeking multiple medical opinions [1], or turning to non-professional sources of help [5].

1.9 Aim of the review

The aim of this review is to summarize current knowledge on Ekbom syndrome, including its clinical presentation, pathophysiology, diagnosis, and treatment options. By combining this with an analysis of selected case studies, we aim to better understand how patients with delusional parasitosis are diagnosed and managed in clinical practice, and to identify the challenges associated with this syndrome.

2. Methodology

The review was based on literature available in the PubMed database. The search was focused on delusional infestation and Ekbom syndrome-related keywords. The selection of the available sources was based on abstract screening. Particular attention was paid to distinguishing articles containing Ekbom syndrome keywords from those referring to Willis–Ekbom disease (restless legs syndrome), as the terminology is often used inconsistently in the literature. Willis–Ekbom disease is a neurological movement disorder characterised by an uncontrollable urge to move, most often affecting the legs [6].

Mostly English-language publications were included, with one publication in Spanish. Ten case studies published between 2020 and 2025 were deliberately selected to reflect the most recent clinical presentations of delusional infestation. To provide broader context, highly cited earlier publications were also included. Studies lacking sufficient clinical detail were excluded.

3. Case Review

3.1 Diagnostic path

In the reviewed cases, the psychiatrist was not always the first specialist dealing with the patients' symptoms. In five cases, the dermatologist was involved before the psychiatric consultation [2, 10, 15, 19, 21]. In four cases a preliminary dermatological diagnosis was made: Norwegian scabies in one patient [19], extensive papule urticaria in another [4], dermographism urticaria in a third [10], and suspected scabies in the fourth case [21]. Three patients received dermatological treatment [4, 10, 21].

A particularly notable case was when a patient believed there was a leech in her vagina so the gynaecologist was actually the first specialist that attended this patient. Due to cultural conditions, this patient has earlier gone to a local faith healer and priest, believing in these non-conventional methods of healing [13].

For some patients the symptoms were so disturbing that on their diagnostic path an emergency department was involved: in two cases a general (somatic) emergency department [20, 21] and two others went through a psychiatric emergency department [2, 10].

The duration of the diagnostic process varied across the analyzed cases, ranging from relatively short periods of a few weeks to several years (in one case, it took as long as 9 years) [5].

3.2 Patient profile

In the analyzed cases, females were a majority (8 cases) and only two cases described male patients. The age of the patients varied from 29 to 81 years. The mean age was 56 years, and the median age was 55.5 years.

The patients suffered from different comorbidities, either psychiatric and non-psychiatric ones. Psychiatric conditions included depression [3, 10, 21] and schizophrenia [4]. There were also two cases with a neurodegenerative disorder - Lewy body dementia [3, 20]. There was one patient with no psychiatric history [2], and for another, potential stressors were mentioned, but no psychiatric diagnosis was made [19].

Regarding somatic conditions, several patients presented with chronic medical comorbidities such as hypothyroidism and irritable bowel syndrome [5], HIV infection and long-term hypertension [15], type 1 diabetes and sleep apnea [21]. In two reviewed cases, no relevant medical history was reported [2, 13].

3.3 Main complaint

Patients' main complaint was a feeling of being infested by different types of living organisms. There were examples of bugs [2, 5, 21] or insects in general [20], ants [3,15], mites [4], worms [10], leeches [13] and scabies [19].

The patients provided different explanations of where the insect had been acquired. It could be either at home [20] or at work [2, 13, 14]. Regarding the origin of the insects, patients provided different explanations: one patient believed that mites could be transmitted from pigeon faeces [4], while another believed that a leech crawled from a field and entered her body through the vagina, reaching the abdomen [13]. One patient believed the parasite was caught at the beach when it crawled through the patient's feet [19]. Regarding beliefs about where the parasites "live," two patients reported that the insects were crawling from their mattresses [4, 19].

The patients had tactile hallucinations and could feel insects crawling under their skin [2, 4, 10, 13, 15, 16, 19, 20], creating a nest on their scalp [3], entering their body and causing an itch [4, 13, 15]. They could also create a sensation in different parts of the body (e.g. limbs and abdomen) [5]. In one case the patient felt a leech crawling inside her vagina [13]. Another patient had a sensation of ants coming out through different parts of their body e.g. eyes, ears and armpits [15]. Another patient could feel scabies in their mouth, and according to what the patient believed in, potentially reach their brain [19].

The patients also presented visual hallucinations and claimed that they could see these different living organisms [2, 3, 13, 15, 21], the worm eggs [10, 21], emerging fibers from the skin [19]. One of the cases is an example of folie à deux and the patient's husband could also "see" the leech that infested the patient [13]. In other cases the social environment was denying the existence of the insects the patients could see, but the patients were resistant to these suggestions. One patient could also hear insects making whistling and buzzing noises [3].

Due to the itch and in order to remove these "parasites", the patients tried different methods. They tried to remove them in different ways e.g. using tweezers [2] or just scratching their skin [3, 10, 15], picking them up and flushing in a toilet [15].

They also acted in a way to avoid potential further infestation e.g. avoiding sleeping on the infested mattress [4].

In an attempt to eliminate the perceived insects, patients used various methods, including the use of over-the-counter antiseptics [5], bathing with bleach, discarding clothing [19], and undertaking disinfestation measures [20].

They also brought in jars or plastic bags with their "findings" (usually including skin flakes) to the medical appointments [5, 13, 19, 21] or picked and crushed the insects in front of the doctor [15]. One patient used a handheld magnifier to demonstrate the insects [21].

3.4 Additional symptoms

The patients presented different psychiatric conditions but in the reviewed literature it was not always clear whether the symptoms were just accompanying the Ekbom syndrome or were a cause or a consequence of the syndrome. The most common were depressive symptoms in general [2, 3, 10, 13, 20], including sleep disturbances (although depression was not diagnosed for all patients with the sleep issues) [2, 4, 5, 13, 19, 21]. Some patients also presented nutritional or gastrointestinal complaints [2, 5, 10] and anxiety [10, 13, 19, 21].

Social distancing was also observed in some of the cases, either by general social withdrawal [5, 20] or by specific actions related to believing in "bugs" and not allowing other people to touch the "infected" patients' belongings and avoiding sharing a bed to avoid transmitting the parasites [4, 15]. One of these patients also avoided public gatherings such as church because of scratching [15]. Additionally, one patient spent a significant amount of time on cleaning and disinfection behaviors, which led to social withdrawal. It is worth noting that the patient was so preoccupied with these behaviors that they caused a car accident while clearing the windscreen during driving [20].

The patients lacked or had poor insight into their condition and disagreed with the logical explanation of symptoms provided by medical professionals or family members [2, 3, 4, 5, 10, 13, 19].

3.5 Mental, cognitive and physical examination

Based on the information reported in the case studies, some patients underwent mental status and cognitive function tests. Three patients underwent the Mini-Mental State Examination (MMSE), and two obtained results within the normal range [2, 3], while one patient scored below this range (receiving 22 out of 30 points) [10]. One patient underwent both the MMSE and the Montreal Cognitive Assessment (MoCA), and although the results were not shared, the score indicated a decrease in functional independence [20]. Another patient who took only the MoCA test scored 26/30 [15].

On physical examination, the most common findings were skin lesions resulting from scratching. The scars were at various stages of healing, showing that the process of skin manipulation had lasted a longer time [2, 10, 15]. Some lesions also showed signs of inflammation, postinflammatory hyperpigmentation, and hemorrhagic crusts [2, 4, 19, 20]. The lesions were most often distributed on the upper and lower extremities [4, 19, 20], as well as on the patients' backs [19, 20]. In particular cases, lesions were also found on the thigh [2] and on the whole body, except for the face and neck [15]. In the unique case of a parasite infesting the vaginal region, bruises were found on the inner vulva and there were scratches in the lower abdomen [13].

3.6 Laboratory and imaging diagnostic

Across the reviewed cases, patients underwent various diagnostic tests. Basic laboratory tests were performed and revealed no significant abnormalities [2, 4, 10, 13, 15, 19]. In one case, monoclonal gammopathy was detected, but hematology consultation excluded the possibility of a malignant hematologic neoplasm [20]. No dysfunction of the thyroid, kidneys, or liver was identified [4, 13, 15, 19], although mildly elevated liver parameters were noted in one case [10]. For cases where these tests were mentioned, urinalysis was unremarkable [2, 4, 19] and stool tests showed no pathological findings [10, 21]. Brain computed tomography revealed either no significant abnormalities [2], age-appropriate cerebral atrophy [10], or nonspecific findings insufficient to explain the patient's condition [20]. Brain MRI demonstrated age-related atrophy and microangiopathy in one case [3], while no abnormalities were found in another [15]. One patient underwent abdominal X-ray and ultrasonography and both showed no abnormalities [13].

3.7 Diagnosis

The diagnosis of primary delusional parasitosis was made in two patients [10, 13]. In two cases, it was not fully clear whether the condition was primary or secondary (in one case, no prior diagnosis had been made before the onset of delusional parasitosis, although a significant life event that could have led to a marked decrease in mood was reported) [5, 19].

In the remaining cases, delusional parasitosis was secondary to other conditions, including psychiatric disorders such as depressive disorder and schizophrenia [2, 4], neurodegenerative conditions such as Lewy body dementia [3, 20], the use of medication (lisdexamfetamine) [21], and, in one case, a somatic disease (HIV) [15].

3.8 Treatment strategies

At first, some patients sought help from spiritual leaders [13, 15] or engaged in self-medication with antiparasitic drugs [10]. When treated by physicians, most patients received antipsychotic therapy, most commonly risperidone [10, 13, 19, 20]. When not used as a first-line option, risperidone was introduced later in the treatment course after other medications (e.g., pimozide) proved ineffective [4]. In one case, although risperidone produced a positive therapeutic effect, it was replaced with paliperidone palmitate due to poor adherence [20].

There were also cases in which patients benefited (at least partially) from treatment with olanzapine [2, 5], clozapine [4], or haloperidol [15].

As some patients presented with depressive symptoms, mirtazapine [2] or selective serotonin reuptake inhibitors (SSRIs) [3, 15] were added to the treatment regimen. Anxiolytic treatment included various benzodiazepines (e.g., alprazolam, clonazepam, diazepam) [10, 13].

For one patient with a delusional parasitosis secondary to Lewy body dementia, the introduction of rivastigmine led to the resolution of Ekbom syndrome symptoms [3].

In one case involving a patient with ADHD, antipsychotic therapy was ineffective; however, discontinuation of lisdexamfetamine resulted in the resolution of delusional infestation symptoms [21].

In several cases, non-pharmacological interventions were used alongside pharmacotherapy, including electroconvulsive therapy [4], distress tolerance training and behavioral activation [5], and psychotherapy [15].

In six cases, symptoms fully remitted [2, 3, 13, 15, 20, 21]. In two cases, patients did not attend follow-up visits, so treatment outcomes could not be assessed [10, 19]. In two additional cases, only a partial response to treatment was observed [4, 5].

4. Discussion

The reviewed cases showed that Ekbom syndrome remains a challenge in clinical practice. In the analyzed articles, patients sought help from dermatologists, other non-psychiatric specialists, or in non-conventional ways. In some cases, emergency departments also needed to be involved.

In terms of clinical presentation, the reviewed cases were heterogeneous in certain aspects. A wide variety of insects were reported as the source of infestation. Although the skin was the most commonly affected site, there were also atypical presentations, such as involvement of the vagina or perception of insects inside the head. Apart from the fixed belief of being infested, some patients also reported seeing the insects. Additionally, as patients attempted to remove the perceived parasites, they caused self-inflicted skin lesions, which made establishing a psychiatric rather than dermatological diagnosis even more difficult. This indicates that patients with Ekbom syndrome may present to specialists from different medical fields, which underscores the importance of broader awareness of the condition across disciplines.

Regarding the patients' profile, the observations from the selected cases are consistent with the literature. As expected, female patients formed a majority (eight out of ten cases). The mean age of the analyzed patients was 56 years, while according to the literature the mean age is 57 years. However, the age range of the analyzed patients (from 29 to 81 years) indicates that clinical suspicion should not be limited to middle-aged individuals.

As reported in the reviewed literature, psychiatric comorbidities such as depressive symptoms, sleep disturbances and anxiety were observed. However, in several cases it remained unclear whether these conditions represented predisposing factors, consequences of the syndrome, or coexisting disorders. This overlap is a limitation in the diagnostic process and may lead to underdiagnosis and misclassification of the condition. It was also observed that the syndrome led some patients to social withdrawal, which may further worsen other psychiatric symptoms and make treatment more difficult.

The diagnostic pathways presented in the reviewed cases were variable. Clinicians differed in the selection of laboratory, imaging and psychological assessments. This complicated comparison of the presented cases and limited the possibility of drawing conclusions regarding optimal diagnostic strategies for future cases of the syndrome.

Despite the diagnostic challenges, in the majority of cases, patients experienced at least partial remission of symptoms following treatment. Antipsychotic medication, particularly risperidone, was the most commonly used therapeutic approach, which is consistent with current literature. The analyzed sources also highlighted the importance of treatment

individualization and flexibility in pharmacotherapy. Moreover, in cases of secondary delusional infestation, addressing the underlying condition appears to be a crucial part of effective management.

We acknowledge that this review is based on a limited number of cases, which reflects the variability of the syndrome. In addition, the included case reports differ in their level of detail and focus on different clinical aspects. Therefore, it cannot be excluded that certain features described in one case may have also been present in others but were not reported. Despite these limitations, we believe the synthesis of available cases may contribute to a better understanding of the syndrome and its diverse clinical manifestations.

5. Conclusion

Ekbom syndrome is a rare psychiatric disorder characterized by a fixed belief of parasitic infestation, often accompanied by tactile hallucinations and other psychiatric symptoms. Although it most commonly affects middle-aged women, it may occur across a wide age range and in both sexes, with variable clinical presentation.

The reviewed cases highlight important diagnostic challenges, including delayed recognition, frequent initial presentation to non-psychiatric specialists, and the lack of a standardized diagnostic pathway that could guide clinicians.

Antipsychotic medications, particularly risperidone, remain the mainstay of treatment, with generally favorable outcomes. However, the findings emphasize the importance of tailoring treatment to the underlying cause, as Ekbom syndrome is often secondary to other conditions. Improving awareness of Ekbom syndrome among non-psychiatric clinicians is essential to facilitate earlier recognition and initiation of appropriate treatment. Further research is needed to establish more standardized diagnostic pathways and optimize management strategies.

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