The Alice in Wonderland Syndrome: A Mixed-Method Exploratory Analysis of AIWS Experiences

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"It's no use going back to yesterday, because I was a different person then."
(Alice in Wonderland, Chapter 10, Lewis Carroll, 1865)

Abstract

The Alice in Wonderland Syndrome (AIWS) is a rare neuropsychological disorder impacting somesthetic and visual perceptions, with symptoms ranging from body-image to time distortions.

Objective: to expand current knowledge on the Alice in Wonderland Syndrome (AIWS) by investigating the experiences of individuals with the syndrome through a review of literature and posts on AIWS-specific online support communities.

Methods: This study was conducted as a mixed-method exploratory investigation of AIWS from two independent sources: a meta-analytical review of published scientific literature from 1955 to 2022 and a review of narrative posts from a moderated online forum specific to AIWS. The online forum was purposefully selected after performing a keyword search on electronic databases, and the literature pertaining to AIWS case series were found using Pubmed. The material from both data collection approaches was subsequently analyzed using qualitative thematic analysis, with relevant descriptive data quantified in numerical form. A total of 253 published cases and case series from 1955 to 2022 were identified and of 194 forum posts, 75 narrative cases met the eligibility criteria. Eligible forum cases were restricted to individuals who: were formally or self-identified as having or having had AIWS; and those reporting a family member's experience with AIWS.

Results: Valuable insight into informational versus emotional needs of individuals with AIWS was brought to light. Support was sought through voluntary sharing of knowledge, personal reactions, diagnostic concerns and symptom-management advice. Medical interventions were more prevalent in published data, with an etiological/neurological focus- infectious causes in children and migraines as an associated condition in adults- as well as a pharmacological one. A potential familial or genetic component of AIWS additionally arose from forum cases. A prevalence of the onset of AIWS in pediatric populations, personal and environmental reactions, cultural factors and a lack of knowledge contributed to underreporting. Nosographical differences further hindered the early diagnosis of AIWS and the lack of appropriate interventions.

Conclusion: A patient-centered experiential and functional approach to the classification of AIWS symptoms and ensuing symptom-management options could help populations feel seen, heard and understood, aid reporting and increase access to early intervention and coping techniques.

Keywords: Alice in Wonderland Syndrome; AIWS experiences; AIWS associated conditions; AIWS classification; AIWS symptom management

1. INTRODUCTION

On the right: Fig. 1. *An illustration by John Tenniel from Lewis Caroll's novel Alice in* Wonderland (1865) depicting metamorphopsia.

Lewis Carroll's beloved children's book *Alice's Adventures in Wonderland* (Carroll, 1865) details the fantastical escapade of a young girl who, upon falling asleep, follows a rabbit down a rabbit hole. She finds herself encountering peculiar creatures and navigating obstacles turning her mishap into a journey of self-discovery, acceptance and determination. Alice experiences changes that impact her self-concept and worldview. These changes include modifications in her own bodily shape and size, depersonalization and altered time perception. She admits that "being so many different sizes in a day is very confusing", when answering the Caterpillar's questions pertaining to her identity (Carroll, 1865). Upon resisting an ensuing attack from playing cards after confronting the tyrannical Queen during a trial for theft, Alice awakens from her dream. For some individuals, Alice's experiences are eerily familiar, and not part of a dream. Distorted experiences in their own body or environment are part of their daily reality. Such isolated visual and somesthetic distortions have been named and described in scientific literature in association with neuroticism, epilepsy, migraines and cerebral lesions from the late 19th century (Blom, 2016). The link to Lewis Carroll's protagonist however, was brought to light in 1952, when neurologist Caro Lippman described transitory "hallucinations" related to body image and unusual bodily sensations in the context of migraines in seven patients. One of these patients specifically referenced Lewis Carroll's Through the Looking Glass characters Tweedledum and Tweedledee (Carroll, 1871) when describing feeling abnormally "short and wide" while walking (Lippman, 1952). In 1955, psychiatrist John Todd paralleled Alice's experiences of "hyperschematia, hyposchematia, derealization, depersonalization, and somatopsychic duality" (Todd, 1955) with the somesthetic, visual and time distortions described by six patients, grouping these symptoms under the term "the syndrome of Alice in Wonderland" (AIWS).

Fig. 2 (a) and (b). Illustrations by John Tenniel from Le*wis Caroll's novel Alice in Wonderland (1865) depicting microsomatognosia and* macrosomatognosia.

In the 70 years since Todd coined the term AIWS, 253 case descriptions have been published in the literature, with comprehensive systematic reviews (Lanska et al., 2013; Blom, 2016; Mastria et al., 2016) and a research overview (Hossain, 2020) contributing to the study of this rare perceptual disorder.

In 2013, neurologist Douglas Lanska and researcher John Lanska classified AIWS symptoms into three typologies. AIWS Type A (9%) was characterized by somesthetic-perceptual distortions related to one's body; individuals with Type B (75%) exhibited visual-perceptual distortions or metamorphopsias and people with Type C (16%) had co-existent somesthetic and visual distortions (Lamska et al., 2013)..

Where some authors, elaborating upon Lanska and Lanska's classification, categorized depersonalization, derealization and time distortions as being facultative symptoms of Todd's syndrome (Mastria, 2016), others considered including these symptoms in type C of Lanska et al.,'s taxonomy (Perdices, 2018). Douglas Lanska and John Lanska later reviewed their classification process in stating that isolated symptoms of dysmetropsia (visual illusions) without any somesthetic-perceptual disturbances must be discouraged from being identified as AIWS (Lanska et al., 2018). Clinical Psychiatrist Jan Dirk Blom, writes, however, that some of his patients with AIWS experience micropsia (seeing objects as disproportionately small) or macropsia (seeing objects as disproportionately big), without the accompanying feeling of their own body changing size (Blom, 2020).

Data also seems to show that the condition is more prevalent in younger populations than older ones. For example, in 166 cases with reported ages from Blom's scientific review of literature until 2016, there were 132 children for 34 adults. Yet, depending on the onset of symptoms, the identified adults may have suffered from AIWS for decades. Furthermore, for the overall population studied, only 46.7% of patients had full remission from the condition (Blom, 2016). The experience of AIWS therefore appears to have developmental and longitudinal implications that cannot be ignored.

In addition to nosographic and developmental differences, there is still a scarcity of cases studied since 1955, despite publication trends reflecting an increased interest in AIWS over the last decade, with a peak of 17 publications in 2018 (Hossain, 2020). Population studies are nevertheless crucial in providing the awareness, early diagnosis, intervention for symptom management and treatment options for individuals with AIWS. Todd's words in explaining the rarity of cases in scientific journals of the time still ring true, today: "The infrequency of reference to the syndrome in the literature is explained by the reluctance of patients to discuss symptoms so far removed from normal experience" (Todd, 1955).

With the advent of information technologies, the use of the internet as a gateway to knowledge and increased communication has blossomed. It has also led to the creation of discussion forums allowing users to investigate health-related topics, discuss sensitive topics, share experiences and benefit from social support; despite potential privacy, trolling and trigger-related risks related to online postings (Dosani, 2014). Online forums can therefore provide researchers with rich qualitative data (Robinson, 2001; O'Brien, 2010), especially in the case of rare, underrepresented or unreported conditions.

2. OBJECTIVES

The aim of this study was to expand current knowledge on the Alice in Wonderland Syndrome experiences by:

1) Comparing data from relevant published cases of AIWS with that of narratives from online support communities to better understand the value of multimodal research in identifying:

- reasons for the lack of reporting
- associated conditions and etiology
- neurological and biological correlates
- concerns and needs
- treatment options and symptom-management strategies for individuals with AIWS

2) Proposing a nosographic classification system that encompasses the experiences of individuals with AIWS to help diagnose the condition more effectively
3) Making recommendations for new avenues of clinical research into AIWS

3. MATERIALS AND METHODS

3.1 Design and datasets

This study was conducted as a mixed-method exploratory investigation (Creswell and Plano Clark, 2011) of AIWS from two independent sources: a meta-analytical review of published scientific literature from 1955 to 2022 and a review of narrative posts from a moderated online forum specific to AIWS.

The online forum was purposefully selected after performing a keyword search on electronic databases. Although the forum discussion threads were publicly accessible, participation in them required forum membership. Prior to beginning the study, forum moderators were contacted and research objectives shared, in order to abide by terms and conditions of the online support community.

The material from both data collection approaches was subsequently analyzed using qualitative thematic analysis, with relevant descriptive data quantified in numerical form. This mixed-method design allowed for similarities and differences in qualitative and quantitative results from both data sets to be further compared while reflecting the personal nature of AIWS experiences in the populations studied.

3.2 Ethical considerations

Any collected information has been subject to ethical considerations (anonymisation, confidentiality, summarization) to satisfy current data protection legislation. In order to better safeguard the identity and intellectual property of online forum members, keyword descriptors rather than direct quotations have been used in this study's processed data.

3.3 Data analysis

For data analysis purposes, participant ages for both datasets were categorized according to the following groupings: 0-18 years (pediatric group/ children); 19 years and above (adults).

The data analyzed from the published cases and forums pertained to :
1) Date of publication or forum posting
2) Age of onset, sex and reaction to AIWS at the onset of symptoms
3) Associated conditions
4) Symptoms and relevant characteristics (episode length, condition duration)
5) Environmental (family, friends, social groups) and practitioner (mental health, physicians, other professionals) reactions
6) Longitudinal implications and outcomes
7) Coping mechanisms and symptom-management strategies

4. RESULTS

The use of electronic search databases to obtain relevant scientific publications (Pubmed and Google Scholar) inputting the following key terms: "Alice in Wonderland Syndrome" or "AIWS" or "Syndrome of Alice in Wonderland" yielded 159 results. These results were filtered based upon available abstracts to include articles that pertained to diagnosed AIWS and case reports. This allowed for the inclusion of 169 cases reported in the literature until 2015 and 84 since, for a total of 253

published cases and case series from 1955 to 2022. All cross-references were double-checked. The articles were written in English, French, Spanish, Dutch, Italian and Japanese.
For the online community dataset, a total of 194 posts were analyzed, yielding 75 AIWS narrative cases. Eligible forum cases were restricted to individuals who: were formally or self-identified as having or having had AIWS; and those reporting a family member's experience with AIWS (as in the case of young children, parents were primary communicators on the forum).

4.1 Population characteristics

In this study, a total of 328 case descriptions of AIWS from scientific publications and forum posts combined were examined. Sex was mentioned for 318 individuals, with similar proportions of males and females (47%). Age or age categories (children versus adults) were mentioned in 325 cases, with the mean age of onset of AIWS symptoms being 8 years old for the 207 individuals in the pediatric group compared to age 30 for the 118 members of the adult population (see Appendix A).

4.2 Personal reactions at the onset of AIWS symptoms

A total of 86 individuals reported their personal reactions at the onset of AIWS symptoms- of which 78.7% were from forum users, as opposed to 10.7% of cases from published literature. Of those who shared their reactions, 62.8% experienced negative emotions at the onset of their symptoms, 25.6% stated feeling neutral about their symptoms, and only 11.6% found positive uses for their symptoms (see Appendix B).

4.3 Conditions associated with AIWS

The comprehensive review by Blom identified nine etiological groupings characterizing AIWS (Blom, 2016), the categories of which are represented in Table 1, with data from this study's populations.

Table 1. Etiological groups and/or AIWS-associated conditions

Etiological groups and/or associated conditions	Published articles ✻		Online forums and data ✻		Total Population
	Population aged < 18 yo N (%)	Population aged > 18 yo N (%)	Population aged < 18 yo N (%)	Population aged > 18 yo N (%)	N = 326 reports of associated conditions (%)
1. Infectious diseases	42 (34.1)	2 (1.3)	16 (51.6)	-	60 (18.4)
2. Central nervous system lesions	4 (3.3)	17 (10.7)	2 (6.5)	-	23 (7.1)
3. Peripheral nervous system lesions	-	2 (1.3)	-	-	2 (0.6)
4. Epilepsy and Paroxysmal neurological disorders	37 (30.1)	20 (12.6)	2 (6.5)	-	59 (18.1)
5. Migraine	34 (27.6)	75 (47.2)	9 (29.0)	6 (46.2)	124 (38.0)
6. Psychiatric disorders	-	20 (12.6)	1 (3.2)	6 (46.2)	27 (8.3)
7. Iatrogenic/ medication-induced	5 (4.1)	7 (4.4)	1 (3.2)	-	13 (4.0)
8. Substance-Induced (eg. Hallucinogen persisting perception disorder)	1 (0.8)	9 (5.7)	-	-	10 (3.1)
Other/cognitive-related/sensory-related (eg. sensory deprivation, hypnotherapy, memory-attentional impairments)	-	7 (4.4)	-	1 (7.7)	8 (2.5)
Total	123	159	31	13	326

✻ It is also noteworthy to report the following from our data sources:
22/75 = 29.3% of forum users experienced chronic symptoms of AIWS
22/75 = 29.3% of forum users experienced symptoms at bedtime (21/62 or 33.9% of children; 1/13 or 7.7% of adults); and a familial factor was reported in 14/75 forum cases
46.7% of patients had full remission and thus 53.3% had persisting symptoms of AIWS (Blom, 2016)
11.3% of Blom's 150 cases with longitudinal data- had partial remission (2016)

Infectious diseases is the predominant associated condition of AIWS in pediatric populations both in published literature and forums (34.1% and 51.6% respectively), with paroxysmal neurological disorders following closely behind, in scientific literature (30.1%). In adult populations, migraines take the lead as the most frequent condition linked to AIWS (approximately 46-47%). The data above supports similar observations from publications since 2016 (Dugauquier, 2020; Kubota, 2020), connecting these etiological categories to the onset of AIWS in populations studied.

4.4 AIWS experiential themes

Based upon the thematic analysis of published case reports and online forum cases of AIWS, three main experiential themes emerge: personal reactions to experiencing the onset of AIWS symptoms; concerns regarding diagnostic issues; and the need for support in navigating this invasive neurological and perceptual condition.

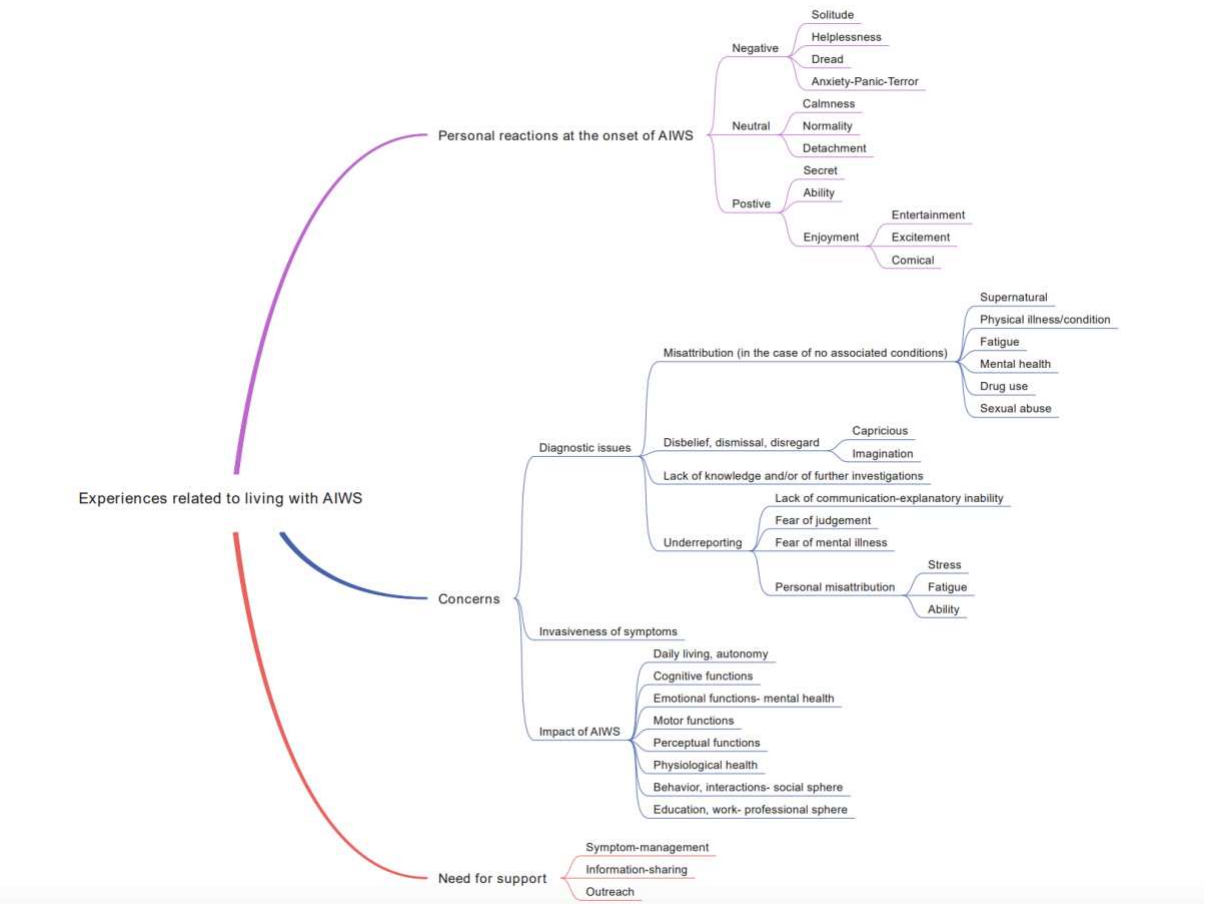

Fig. 3. Thematic map representing the experiences of individuals with AIWS from both the scientific literature and forum datasets

4.4 Theme 1: Personal reactions at the onset of AIWS symptoms

Of 86 reports on personal reactions at the onset of AIWS symptoms, negative reactions, accounting for the majority of cases, ranged from feelings of helplessness and isolation, to anxiety and even terror. Those who felt neutral about their symptoms generally dismissed them or did not realize that they were not typical (especially in the case of younger populations). Of the few who attributed positive feelings to their symptoms, this differed in youthful groups who believed in extraordinary abilities versus adult populations who found their symptoms amusing, or even invested them for personal entertainment purposes.

4.4 Theme 2: Concerns

Main concerns voiced by the AIWS population studied can be grouped into problems related to diagnosing the perceptual disorder, the invasiveness of symptoms- whether in paroxysmal or chronic forms- and the functional impact of AIWS on different spheres of the individual's life. Diagnostic concerns related to misattribution of AIWS symptoms to erroneous factors such as outworldly elements, illnesses, fatigue levels, anxiety and stress, drug use or in one forum case, the inaccurate attribution to sexual abuse, seems correlated to an absence of associated conditions (be it medical, neurological or psychiatric). The environmental disregard and disbelief of AIWS experiences is also a factor raised in the realm of diagnostic concerns, as are the lack of voluntary reporting of symptoms and experiences for fear of judgment, fear of having a mental illness or a personal misattribution and dismissal of symptoms as resulting from stress or fatigue levels.

The impact of AIWS is reported as being wide-ranging according to symptoms experienced by the affected individuals. Daily living and autonomy may be affected in terms of the inability to travel safely, cross roads, drive or even live alone, depending on the severity and frequency of perceptual distortions. Motor and vestibular functions may additionally be impacted by balance issues and dizziness brought on by somesthetic disturbances affecting one or both sides of the body, proprioceptive distortions, or visual disturbances arising from shape distortions (contours being wavy for example), spatial reversals (up ↔ down), and more. AIWS being a perceptual neurological disorder, the recognition and interpretation of sensory stimuli is greatly altered.

The effect of perceptual distortions on cognitive functions have also been highlighted by individuals with AIWS. Issues with focus, task completion, memory, conversational language, reading skills and reaction time are among the cognitive disruptions that were described. Problems with physiological health- nausea, fatigue levels, sleep disorders- also result from dealing with AIWS, according to populations studied. The detrimental influence of AIWS on emotional functions and mental health seems to take form in emotional lability, feelings of helplessness and a lack of control, a decrease in self-confidence and self-efficacy levels, increased stress and anxiety, the occurrence of panic attacks, the emergence of phobias (claustrophobia, fear of darkness), and in two self-reported forum cases, suicidal ideation. Social interactions are another sphere of impact: feelings of isolation and an inability to communicate one's experiences with others being typical of people with AIWS. In the professional sphere, educational issues stemming from the cognitive impact of AIWS (reading and focusing in class and at work) and for some, the inability to work, due to symptom duration and severity have been disclosed.

4.4 Theme 3: Need for support

Where individuals from published cases of AIWS often sought support for symptom-management at medical centers and were treated for underlying associated conditions (see Table 1), forum users in need of support posted threads specific to symptom-management, information-sharing and outreach. Various medical investigations into symptoms of AIWS were reported 16 times in forum users compared to 153 counts for published cases, in childhood populations. A similar discrepancy was found in counts for adult populations: 3 for the online forum compared to 129 for published case reports. Additionally, medical treatments were accessed by 93.9% of published cases based upon available symptom-management data post consultation, whereas for online community members, such treatments were limited to 9.7% of the forum population. Forum use often served the purpose of reducing feelings of isolation or understanding evolving symptoms of AIWS. Indeed, 29.3% of forum members experienced chronic and longitudinal symptoms of AIWS (see Table 1). In the case of children affected with AIWS, parents were directly involved with the outreach (postings) on online support communities.

5. DISCUSSION

Results can be grouped and analyzed according to the following categories: prevalence and reporting issues; diagnostic and nosological considerations; neurological correlates; and AIWS support needs.

5.1 Diagnostic considerations

5.1.1. Reporting

Todd mentioned- already in 1955- that patients are reluctant to talk about experiences that are so unusual compared to that of their surroundings (Todd, 1955), resulting in underreported AIWS symptoms.

The concepts of normality/pathology seem intrinsic to the negative way in which populations with AIWS principally react, at the onset of their symptoms (68.2%, Appendix B). The fear of "judgment" and erroneous attribution of symptoms to a psychiatric condition silence many who suffer from AIWS. Part of the reason behind this is a lack of understanding in distinguishing hallucinations and distortions. Where perceptual distortions are misinterpretations or alterations based upon existing and appropriate sensory inputs, hallucinations are perceptions not founded on sensory stimuli. Health professionals

and individuals with AIWS alike may misattribute AIWS phenomenology to hallucinations rather than distortions, despite differing underlying mechanisms (Borruat, 1999; Naarden, 2019).

On the other hand, disbelief or the dismissal of reported symptoms- by practitioners or family members- also raises diagnostic concerns in populations with AIWS, as both the misattribution and disregard of lived experiences leads to the reduction of etiological investigations and corresponding treatment options. Thus, when faced with disbelief, dismissal or a medical lack of knowledge regarding symptomatology, it is likely that people with AIWS seek answers or support elsewhere, contributing to a lack of published cases in literature.

Cultural factors and prior knowledge pertaining to the syndrome can also play a role in environmental reactions. One family, for example, attributed clinical manifestations to magico-religious causes and sought treatment from a healer (Kadia et al., 2017). In some other cases, having a practitioner or family member be aware of AIWS through personal or academic knowledge of the condition impacts reporting and treatment options for the concerned individuals. Liu's retrospective study of pediatric cases of the syndrome put forth a familial factor of AIWS in 1 out of 48 or 2% of the children (Liu et al., 2014). The self-disclosed familial link in this study's forum data is much higher: with 18.7% of the 75 cases examined having a familial component. This could raise the question of a possible genetic component of AIWS, should actual numbers be higher, knowing that AIWS is generally underreported.

Another factor in the scarcity of reported cases of AIWS is the fact that the syndrome onset occurs more predominantly in childhood than adulthood (with a prevalence of 57.3% cases of children versus 41.5% of adults in the literature; and with 82.7% versus 17.3% in the forums respectively). The average age of diagnosis is 8 years for this study and between 5 to 10 years in literature (Pickerell, 2012). Additionally, the mean age of the onset for youth populations from the online community (7 years) is lower than that in published articles (9 years), with parents reaching out on forums to make sense of their children's symptoms. Children may additionally lack the words in describing their experiences, thus delaying reporting. As Alice herself told the Caterpillar in Carroll's notable book, "I can't explain myself, I'm afraid, Sir, because I'm not myself you see." (Carroll, 1865). The likelihood of misattributing children's symptoms to tiredness (with 21/62 or 33.9% of children from the forum data experiencing symptoms at bedtime), childlike fantasies ("imagination", "play", "whimsicality") or behavioral issues ("capriciousness"), may also contribute to the underestimation of AIWS in the general population.

5.1.2. Phenomenological and classification differences

Jan Blom reported 16 somesthetic and nonvisual symptoms and 42 visual symptoms in his comprehensive review from 2016 (Blom, 2016). Douglas Lanska and John Lanska determined that out of the 81 cases they reviewed in 2018, only 25% met Todd's original inclusion criteria, meaning obligatory somatosensory symptoms determining an AIWS diagnosis (Lanska's Type A) (Lanska, 2018; Viela, 2020). Authors diverge on this nosological criteria, as many have identified isolated visual symptoms in their patients that also warrant the diagnosis (Blom, 2020). Many have also included time distortions, derealization, depersonalization and other non-visual distortions in the Type C classification of AIWS (Lanska, 2013; Perdices, 2018), with some considering them as non-obligatory symptoms (Mastria, 2016). One author proposed to include time distortions as a separate subtype of AIWS (AIWS-T or time-related subtype), with the other subtypes being the: AIWS-V (visual subtype), AIWS-I (intrapersonal subtype taking into account somesthetic-perceptual alterations and including depersonalization/derealization) and the AIWS-M (miscellaneous subtype, with no predominant characteristic) (Shammas, 2020). This study supports the latter, by further proposing to introduce a patient-centered experiential and functional approach to the classification of AIWS symptoms.

In dividing symptoms into a specific intrapersonal and extrapersonal taxonomy, the experience of reality and of time differ in intrapersonal (somatopsychic duality, depersonalization, doom; and the internal experience of quick motion or protracted duration) versus extrapersonal distortions (derealization; distortions of movement, time and auditory-perceptual experiences related to external objects).

Table 2. Proposed classification for AIWS symptomatology

Type A (Intrapersonal experiences)	Type B (Extrapersonal experiences)	Type C (Combination of intrapersonal and extrapersonal experiences)
Somesthetic experiences I. Visual body schema distortions II. Bodily proprioceptive distortions III. Vestibular distortions IV. Other somato-sensory distortions	Visual-perceptual experiences I. Color distortions II. Shape distortions III. Spatial distortions IV. Distance-related distortions V. Distortions of movement and time (in external objects)	Co-existent somesthetic and visual distortions
Experience of reality (intrapersonal/ sense of self) V. Somatopsychic duality VI. Depersonalization and/or ego dissolution VII. Intrapersonal feeling of doom	Experience of reality VI. Derealization	
Chronoception VIII. Time distortions (quick motion or protracted duration in the internal experience of time)	Auditory-perceptual experiences VII. Intensity (soft, loud) VIII. Auditory time distortions (for external objects)	

The classification above aims to report the spectrum of lived experiences of AIWS and assist in both the appropriate and early diagnosis of the syndrome (for a detailed version, refer to Appendix C). This could also potentially lead to pertinent symptom-management interventions for individuals with the condition.

The experiences of people with AIWS both in literature and on online support communities is reflected in Table 3, with the following prevalence rates: visual-perceptual distortions (63.4%), followed by somesthetic (17.1%) and chronoceptive ones (8.4%), alterations in the intrapersonal experience of reality (4.6%), derealization (4.2%) and finally, auditory-perceptual distortions (2.3%).

Table 3. Prevalence of reported symptoms based on the proposed classification

Symptoms	Published articles	Online forums and data	Total symptoms
	N (% of 680 sympt)	N (% of 216 sympt)	N (% of 896 sympt)
Type A symptoms	**177 (26.0)**	**92 (42.6)**	**269 (30.0)**
Somesthetic experiences	**91 (13.4)**	**62 (28.7)**	**153 (17.1)**
I. Visual body schema distortions	82	21	103
II. Bodily proprioceptive distortions	7	29	36
III. Vestibular distortions	1	9	10
IV. Other somato-sensory distortions	1	3	4
Experience of reality (intrapersonal/ sense of self)	**30 (4.4)**	**11 (5.1)**	**41 (4.6)**
V. Somatopsychic duality	4	3	7
VI. Depersonalization and/or ego dissolution	26	3	29
VII. Intrapersonal feeling of doom	-	5	5
Chronoception (internal experience of time) VIII. Time distortions	**56 (8.2)**	**19 (8.8)**	**75 (8.4)**
Type B symptoms	**503 (74.0)**	**124 (57.4)**	**627 (70.0)**
Visual-perceptual experiences	**463 (68.1)**	**105 (48.6)**	**568 (63.4)**
I. Color distortions	27	1	28
II. Shape distortions	295	51	346
III. Spatial distortions	3	7	10
IV. Distance-related distortions	113	35	148
V. Distortions of movement and time (in external objects)	25	11	36
Experience of reality VI. Derealization	**37 (5.4)**	**1 (0.5)**	**38 (4.2)**
Auditory-perceptual experiences	**3 (0.4)**	**18 (8.3)**	**21 (2.3)**
VII. Intensity	2	12	-
VIII. Auditory time distortions	1	6	-

Total number of reported symptoms in published cases (N = 680)
Total number of reported symptoms in the forums (N = 216)
Total number of reported symptoms (N = 896)

The AIWS-types based upon the proposed nosographic distribution in this study stems from 102 total cases. Previous typologies follow Lanska and Lanska's classification (2013), with 9% of cases having type A somesthetic symptoms, 75%

having type B visual symptoms, and 16% having type C: a combination of somesthetic and visual symptoms, not specifically looking into differing intrapersonal and extrapersonal experiences.

Table 4. Prevalence of AIWS-types based on the proposed classification (102 cases)

AIWS-type	Published articles (from 2016)☆	Online forums and data	Total Population
	N (%)	N (%)	N (%)
AIWS Type A (intrapersonal symptomatology)	2 (7.4)	13 (17.3)	15 (14.7)
AIWS Type B (extrapersonal symptomatology)	15 (55.6)	28 (37.3)	43 (42.2)
AIWS Type C (combined intrapersonal and extrapersonal symptomatology)	10 (37.0)	28 (37.3)	38 (37.3)
Undefined	0	6 (8.0)	6 (5.9)
Total	27	75	102

☆ As prior case studies refer to Lanska's classification (2013), with 9% of cases having type A somesthetic symptoms, 75% having type B visual symptoms, and 16% having type C- a combination of somesthetic and visual symptoms.

The classification of AIWS-types reflects the symptomatology of all populations studied, with 42.2% having extrapersonal symptoms (type B: seeing and/or feeling changes in external objects, people or reality), recognizing that 37.3% of AIWS experiences can present a mixed or combined form, and that 14.7% harbor intrapersonal alterations (seeing and/or feeling changes in one's own body/sense of self).

5.1.3. Neural basis of AIWS

Besides diagnostic roadblocks due to a lack of knowledge, misattributions and underreporting engendering a shortage of investigations, even when scanning techniques have been used to examine AIWS symptoms, they have struggled to yield results. For example, for Liu's retrospective study (Liu, 2014), in cases that underwent neuroimaging techniques, 21/21 were unremarkable for MRIs and 23/23 had unrevealing EEGs. Consequently, the few cases where investigations took place during an episode are paramount to identifying brain structures involved in AIWS symptomatology.

Differences in neuroimaging results when comparing episodes of AIWS in children and adults have been demonstrated. In children, a unilateral and bilateral hypoactivation of the calcarine gyrus, as well as hyperactivation in parietal lobules have been observed in fMRIs (Brumm et al., 2010) in addition to SPECT results revealing right-sided hypoperfusion of frontal, fronto-parietal, temporo-occipital and perisylvian cerebral areas (Kuo et al., 1998; Mastria, 2016; Perdices, 2018). Lesions or hypometabolism in right medial temporal, paramedian temporo-occipital and left parietal brain regions have been put forth in adults with AIWS (Kim et al., 2006; Coven et al., 2013; Perdices, 2018; Shah, 2020). The manipulation of the parieto-occipital cortex during a ventricular shunt revision neuroendoscopic procedure also led to a case of adult AIWS (Entezami et al., 2018).

A recent lesion mapping study provides more insight into cerebral regions associated with AIWS symptoms. Of 30 lesions mapped, visual pathways in the right hemisphere (optic tract, extrastriate visual cortex, ventral occipital fasciculus and the inferior fronto-occipital fasciculus in the occipital lobe) were impacted in 72% of individuals with AIWS-type B or extrapersonal visual symptoms (Piervincenzi et al., 2022). Lesions in AIWS-type A and type C cases were scattered with a lack of conclusive spatial overlap, according to this same study, although also localized in the right hemisphere (frontal lobe, insula, thalamus, hippocampal and parahippocampal cortices) (Piervincenzi et al., 2022).

Other authors put forth frontal lobe lesions associated with AIWS-type B symptoms (Morland, 2013), with type-A phenomenology being linked to right ventral posterolateral nucleus (VPL) lesions in the thalamus (ElTarhouni et al., 2020) or hypoperfusion in the frontoparietal operculum (Morland, 2013). Distortions in the sense of sense of self and somesthetic type-A symptoms also seem connected to alterations in visual and somatosensory integration regions or TPO-C junction- an intersection of temporo-occipital, parieto-occipital, and temporo-parietal junctions (Brumm, 2010; Mastria, 2016). PET scans have also shown a hypometabolism in occipital and parietal regions (Yokohama et al., 2017); a hypoperfusion in the primary visual cortex diffusing into the temporo-occipital areas (Landais et al., 2019) and a focal uptake in right cuneus and precuneus regions in SPECT investigations (Mancini et al., 2018). These cortices seem involved in somesthetic, visuospatial perception (cuneus and precuneus) and the integration of sensory inputs (VPL) and hence, related distortions.

Isolated AIWS symptoms have also been associated with specific cerebral regions. Micropsia (perceiving objects as smaller than their objective size) seems related to a hypoactivation of primary and extrastriate visual areas and to the hyperactivation of certain parietal regions (Brumm, 2010). Macropsia (perceiving objects as larger than their objective size), on the other hand, seems linked to lesions in posterior basal temporo-occipital areas (Matsudaira, 2020) and alterations in right occipital regions (Velasquez, 2016). The perception of colors being extremely vivid or hyperchromatopsia, seems connected to changes in a specific region of the visual cortex (V4), while the inability to perceive motion (akinetopsia) is associated with the V5 cortical region (Naarden, 2019). Perceptual distortions pertaining to the location or distance of objects (pelopsia with objects seeming nearer; and teleopsia with objects seeming farther away), relate to left-hemispheric cortical-subcortical lesions (Manchini, Mastria, 2019). Body size misperceptions- micro or macrosomatognosia- seem to involve frontal lobe lesions (Weijers, 2013; Morland, 2013).

Despite singular case studies associating isolated symptoms or AIWS-types to specific brain regions, the lesion-mapping study conducted in 2022 by a group of neuroscientists in Italy determined that regions linked with AIWS are not so clear, especially in types A and C (Piervincenzi et al., 2022). However, even if results from imaging studies are inconclusive at this time, the study of the neural correlates is important in propelling research into the syndrome onwards, just as the identification of associated conditions (infectious diseases in children and migraines in adults) can inform medical practitioners of the possibility that these conditions may lead to perceptual disorders such as AIWS.

5.2 Support considerations

Regardless of symptomatology and varying biological and neural correlates, prognosis of AIWS in literature is deemed positive, with authors stating that symptoms are harmless or resolve spontaneously, in an attempt to inform and reassure affected populations. Yet, based on forum data, this can sometimes be received as a dismissal of their AIWS experience, given the functional impact of symptoms in their personal, educational/professional and social life. Moreover, despite a treatment of the underlying cause or associated condition, in 33% of AIWS cases, symptoms persist (Liu, 2014), full remission occurring only in 46.7% of cases with available longitudinal data (Blom, 2016).

5.2.1. Feeling seen, heard and understood

Having a perceptual disorder such as AIWS can feel lonely. Some forum members reported relief at not being alone in experiencing “curiouser and curiouser” (Carroll, 1865) phenomena. Others found ways to deal with symptoms, with episodes lasting between 5-30 minutes to 24 hours daily; and syndrome duration ranging from a single occurrence (Perdices, 2016), weeks (Kadia et al., 2017) or months (Omata et al., 2016) to decades (forum case 63: 40 years of AIWS with 24/7 symptoms for 13 years).

Reporting of AIWS on online support communities included affective elements such as reactions at the onset of symptoms and beyond. Personal emotional reactions were shared in safe, albeit virtual spaces- reducing users’ feelings of solitude and increasing those of connectedness, as they read through and responded to posts mirroring their experiences. Validated that it wasn’t simply their imagination running wild, forum users often provided firsthand accounts of living with AIWS: they felt seen, heard and understood. Over 78% of forum users thus willingly shared emotional reactions (negative-neutral-positive at

the onset of AIWS; and relief or gratitude at relating to other user experiences), compared to data gathered from studies (10.7% of cases sharing affective information). One public forum user stated that the syndrome's name- in reference to a children's literary character- helped reduce how frightening it felt by experience. For other forum users, the familial factor seemed to bond family members with a shared understanding, although some were at a loss in addressing symptoms in their children, despite having experienced the phenomenon in their own youth.

A predominance of emotional elements in posts pertaining to mental health, neurological disorders or critical conditions in online support groups has been evidenced in research (Deetjen et al., 2016). The invasive nature of symptoms clearly exacerbated the stress experienced by people with AIWS and parents of children with the condition- who all sought support on forums or from health professionals and medical centers. Informational elements on the other hand, were found in both forum data and scientific literature. Published cases, however, offered more insight into biological investigations, medical care or pharmacological prescriptions given to treat associated conditions of AIWS.

5.2.2. Symptom-management and treatment implications

Support from family members or health practitioners assist individuals in their search for information and symptom-management. The types of consultations and practitioners referred to in this study are: primary investigations with neurologists/neurology centers, migraine centers and psychiatrists/therapists; and auxiliary investigations with ophthalmologists and ENT specialists. A familial factor of AIWS, in terms of multiple family members having experienced the syndrome, can also support the need for screening and longitudinal follow-ups, in gaining understanding of mechanisms involved in the disorder. Interestingly, familial factors emerged predominantly from forum data as opposed to published literature, with the need to find more information if the lack of knowledge or communication (not speaking of the disorder) persisted in some families.

Published cases, on the other hand, offered more information on specific medical examinations and treatments, in the event of patient data on the syndrome's course and outcome. Examples of investigations include: general check-ups (BP, bloodwork), neuro-imaging techniques (EEG, CT, PET, SPECT, MRI). Out of 107 treatment counts in scientific literature addressing underlying conditions, 3 were linked to treating infectious diseases (Kadia et al., 2017; Paniz-Mondolfi et al., 2018; Kubota et al., 2020), 92 were given antiepileptics/anti-migraine medication (Blom, 2016; Camacho Velasquez, 2016; Beh et al., 2018; Garcia-Cabo, 2019; Mastria et al., 2018; ElTarhouni, 2020; Matsudaira et al., 2020), 3 were given thermoregulators (Yokohama et al., 2017; Chirchiglia, 2019; Mudgal, 2021), 2 were given antipsychotic medication (Yokohama et al., 2017; Mudgal, 2021), 1 had a modification in psychostimulant dosage (Dugauquier et al., 2020), 2 had Electroconvulsive therapy (Blom, 2016), 1 transcranial magnetic stimulation (Blom, 2016), 1 patient had surgery (Mastria et al., 2018) and 2 treatments were non-pharmacological (Mastria et al., 2018).

Additionally, alternatives were offered on online support communities as users shared their own knowledge and experiences with investigations and treatment options. Forum users offered laypersons advice on diet (fish oil, paleo diets), eye equipment (Irlen lenses) and specific tests to assess malabsorption of simple carbohydrates (Hydrogen breath test for fructose malabsorption) potentially associated with AIWS symptoms.

People with chronic or recurrent AIWS have had to learn to manage their condition in an adaptive way, should symptoms evolve for those who first encountered the syndrome as children and subsequently as adults. Main symptom-management approaches based upon lived experiences of AIWS- whether episodic, recurrent or chronic- and identified through content analysis, are listed in Table 5.

Table 5. Main coping and symptom-management techniques in the context of AIWS

Coping and symptom-management techniques	Published articles	Online forum	Total Population
	N (%) 114	N (%) 113	N = **227** reports of coping mechanisms/ treatments (%)
Avoidance/ minimisation of symptoms	-	4 (3.5)	4 (1.8)
Holding environment/ reassurance (temporary time frame)	1 (0.9)	9 (8.0)	10 (4.4)
Acceptance/tolerance of symptoms (accustomation)	-	2 (1.8)	2 (0.9)
Medical or pharmacological treatments (benadryl, anti-epileptic, anti-migraine, *ibuprofen…)*	107 (93.9)	11 (9.7)	118 (52.0)
Diet (fish oil, paleo diet)	-	4 (3.5)	4 (1.8)
Movement/Exercise	1 *(didn't work)* (0.9)	3 (2.7)	4 (1.8)
Art/play (mutualistic benefit; fantasy)	1 (0.9)	7 (6.2)	8 (3.5)
Investing symptoms (exaggeration, control)	-	5 (4.4)	5 (2.2)
Redirecting attention (reading, avoid starting at objects)	1 (0.9)	8 (7.1)	9 (4.0)
Sensory integration (pressure points, concentration, individual, object focus, reality focus)	-	16 (14.2)	16 (7.0)
Reduction of sensory demands (close eyes, decrease the warmth/temp in room, meditation)	1 (0.9)	13 (11.5)	14 (6.2)
Intellectualization (trends, books, research) especially as adults	-	16 (14.2)	16 (7.0)
Outreach (especially as adults)	-	11 (9.7)	11 (4.8)
Other tools (Irlen lenses, therapies such as CBT, counseling)	2 (1.8)	4 (3.5)	6 (2.6)
Total	114	113	227

Of 227 reports of coping and symptom management techniques identified in this study's published and forum populations, the majority are linked to medical and pharmacological treatments overall (52.0%). Having said that, the primary mode of coping for forum users nevertheless relates to taking individual control of symptoms (through sensory integration strategies: 14.2% of online forum users) or taking an intellectual approach in addressing the syndrome (gaining more knowledge through research, reading articles and books; or finding patterns in their own phenomenological experience: 14.2% of forum members).

The rich qualitative data from AIWS-specific forums stems from intrinsic characteristics of online support communities. Participants can live all over the globe, and can connect with one another through information technology rather than physical or geographical location. Because the forum was based on the common goal of finding out more about AIWS, individuals with the condition and their relatives were more likely to explore sensitive topics in posts: they sought advice from people who could relate to their experiences with the syndrome. The potential anonymity of forum members (when signing up via a self-created email account), the role of moderators in ensuring a safe online experience for users (in language use, limiting spams, promoting exchanges and deleting inappropriate posts) all contribute to varied and abundant virtual discussions.

5.3 Limitations of this study

This research has limitations, such as a potential data bias due to sparse availability of data on AIWS, be it in publications or online forums. The different manner in how data was obtained- through a review of scientific literature or of spontaneous postings- could also be a methodological limitation in terms of comparability of data for this mixed-method exploratory investigation. In spite of this, data from forum posts complemented that from publications, especially in the case of information on symptom-management and personal reactions at the onset of AIWS. Data extraction and abstraction by one independent researcher rather than multiple observers may also have impacted data validity. An effect size due to 253 published cases compared to 75 online ones, could similarly bias quantitative values in this study's processed data tables. Additionally, in order to protect the privacy of the cases studied, population characteristics such as nationality and specific quotes from forum posts were not used. This could impact the generalizability of findings on AIWS due to partiality leaning toward certain contributing countries and authors for published data; and to certain nationalities or language-based skills for forum posts. Indeed, the English language was used to communicate in posts from the online support community, and regarding scientific literature, the top contributing countries were the US, Japan, Italy, Germany, Spain, France, Turkey, Australia, the Netherlands, the UK, Canada, Israel and Taiwan (Hossain, 2020). This means that populations from many countries in Africa, Asia, South America and northern Europe were underrepresented. Differential access to technology could also limit the populations that are sharing AIWS experiences online. These factors can therefore affect the generalizability of findings in terms of accounting for cultural differences, as seeking alternatives to medical treatment methods for AIWS was minimal in published articles, and the English-speaking forum users came mainly from Western societies.

5.4 Avenues for further research

Completing this study nevertheless attests to the scarcity of research into AIWS experiences both in children and adults.

It is thus crucial that more studies:
1) investigate qualitative AIWS experiences to provide avenues for increased awareness regarding the condition to: reduce underreporting, acknowledge the variability of experiences (symptoms, AIWS-types, condition duration and episode length; effective coping mechanisms) and help populations feel seen, heard and understood, when navigating this rare perceptual disorder.
2) increase longitudinal medical and clinical research into AIWS, to further develop factual, etiological, phenomenological, neurological and AIWS symptom-management knowledge in both general population and in medical communities.
3) explore population differences in associated conditions with the knowledge that certain conditions may lead to perceptual disorders such as AIWS (infectious diseases in children and migraines in adults; neurological procedures such as neuro-endoscopies demonstrating the fragility of cortical fibers, leading to AIWS for some individuals).
4) pursue work on classifying symptoms and championing the entry of AIWS as a perceptual spectrum disorder into diagnostic manuals (DSM-V, ICD-10) with the goals of: increasing appropriate diagnoses and providing purposeful interventions to help affected populations manage symptoms that impact their emotional, cognitive, behavioral, physiological and social spheres of life.
5) encouraging research into online support communities as providing complementary information to empirical studies, with their utility to healthcare information, discussion and support to be further investigated.

6. CONCLUSION

This research sought to give a voice to individuals with the Alice in Wonderland Syndrome, given the rarity of the disorder and lack of reporting due to environmental and medical dismissal, lack of knowledge and personal fear of mental health-related diagnoses.

Increasing awareness levels and advocacy efforts may help people with AIWS access resources and interventions earlier, diminishing the feelings of isolation and hopelessness experienced by those with AIWS. This explorative approach using published and forum data allowed for the examination of lived experiences of people with AIWS beyond symptomatology or etiologies: this study thus also took into account familial factors, personal and environmental reactions, the longitudinal impact of rare disorders, and the types of coping mechanisms implemented by individuals with AIWS.

Demystifying rare diseases and using modern tools to connect populations with each other can only help foster more equitable practices when dealing with people presenting with unusual experiences. Alice's words: "it's no use going back to yesterday, because I was a different person then," can thus become a positive change embodied by those who access newfound knowledge and empathy by learning about experiences "so far removed" from their own.

CONFLICTS OF INTEREST

None.

APPENDIX A

Population characteristics

	Published articles		Online forums and data		Total Population	
	N (%)	Mean	N (%)	Mean	N (%)	Mean
Sex						
Male	118 (46.6)	-	35 (46.7)	-	153 (46.6)	-
Female	128 (50.6)	-	27 (36.0)	-	155 (47.3)	-
No sex info	7 (2.8)	-	13 (17.3)		20 (6.1)	-
Total	253	-	75	-	328	-
Age at AIWS onset		Mean age at onset (years)		Mean age at onset ✻ (years)		Mean age at onset (years)
< 18 yo	145 (57.3)	9	62 (82.7)	7	207 (63.1)	8
> 18 yo	105 (41.5)	35	13 (17.3)	25	118 (36.0)	30
No age info	3 (1.2)	-	-	-	3 (0.9)	-
Total	253	-	75	-	328	-

✻ calculated from specific ages when given (n = 42 for the forum data)

APPENDIX B

Valency of personal reactions at the onset of AIWS symptoms

	Published articles		Online forums and data		Total Population	
	N (%)⁕	Mean	N (%)⁕	Mean	N (%)⁕	Mean
Negative (-)	14 (51.9)	-	40 (67.8)	-	54 (62.8)	
Neutral (0)	11 (40.7)	-	11 (18.6)	-	22 (25.6)	-
Positive (+)	2 (7.4)	-	8 (13.6)	-	10 (11.6)	-
No reported reaction	226	-	16	-	-	-
Total reported reactions	27 (10.7)	-	59 (78.7)	-	86 ✢	-

⁕ Of reported reactions

✢ 26.2% of the total population studied (n= 328) reported reactions at the onset of AIWS symptoms

APPENDIX C

Proposed classification for AIWS symptomatology (detailed version)

Type A (Intrapersonal experiences)	Type B (Extrapersonal experiences)	Type C (Combination of intrapersonal and extrapersonal experiences)
Somesthetic experiences I. Visual body schema distortions Microsomatognosia Macrosomatognosia Achematia Hyposchematia Hyperschematia II. Bodily proprioceptive distortions Pressure Touch Levitation Experience of size, position of body parts (a feeling of change, not visually-based) III. Vestibular distortions Disorientation Dizziness Falling sensations III. Other somato-sensory distortions IV. Other somato-sensory distortions Olfactive Gustatory Thermoceptive Auditory (one's own voice)	Visual-perceptual experiences I. Color distortions Achromatopsia Chromatopsia Dyschomatopsia Hyperchromatopsia Erythropsia and tinted vision II. Shape distortions Dysmorphopsia Hemimetamorphopsia Micropsia Macropsia Prosometamorphopsia Illusory splitting Polyopia III. Spatial distortions Stereoscopic vision Plagiopsia Spatial reversals (up ↔ down) IV. Distance-related distortions Zoom vision Teleopsia Pelopsia Proxiopia V. Distortions of movement and time (in external objects) Akinetopsia Kinetopsia Slow and fast motion in external objects	Co-existent somesthetic and visual distortions
Experience of reality (intrapersonal/ sense of self) V. Somatopsychic duality VI. Depersonalization and/or ego dissolution VII. Intrapersonal feeling of doom Doom Dread	Experience of reality VI. Derealization	
Chronoception (internal experience of time) VIII. Time distortions Quick motion phenomena Protracted duration phenomena	Auditory-perceptual experiences VII. Intensity (soft, loud) VIII. Auditory time distortions (slow, fast speaking/ sounds- for external objects)	

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