

Medically unexplained visual loss in children and young people: an observational single site study of incidence and outcomes

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Abstract

Purpose To determine the incidence of medically unexplained visual loss (MUVL) in children in an open access children's eye casualty.

Patients and methods We collated demographic and clinical data of consecutive patients younger than 16 years who presented to the children's eye casualty at Moorfields Eye Hospital over a 12-month period and were diagnosed with MUVL or suspected MUVL. We reviewed the clinical records at least 3 months after initial presentation. We calculated the incidence using the number of 'new patient' attendances over the same period as denominator ($n = 2397$). We used descriptive analysis. Main outcome measures: number of patients diagnosed with MUVL, proportion of patients with a history of or present psychological problems, recovery rate, and improvement in visual acuity.

Results We identified 85 cases of MUVL (54 females; median age: 9 years (IQR 7–12)). The median duration of follow-up was 1.2 months (IQR 0–4.3). The estimated annual incidence was 3.5% (95% confidence interval 2.9–4.4%). Thirty-three per cent of children had a history of psychiatric disorders, reported a stressful life event, or showed signs of psychiatric disorder at the time of first presentation. The recovery rate was 25%. Median improvement in best-corrected visual acuity from presentation to last appointment was 0.22 (IQR 0.06–0.43) logMAR.

Conclusion The incidence of MUVL is higher and the rate of resolution lower than previously reported. MUVL may be associated with mental health problems. We recommend screening for psychological problems to facilitate access to psychological treatment.

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Introduction

Medically unexplained visual loss (MUVL) describes visual loss or visual symptoms in the absence of any medically detectable eye, visual pathway, or brain condition. It is classified as a conversion disorder, in DSM-5, that is, a functional neurological symptom disorder resulting in loss of function. As with other medically unexplained symptoms, there is no universally accepted definition.¹ A number of different terms are used to describe the condition, and terminology has evolved over time (MUVL, non-organic visual loss, functional visual loss, hysterical visual loss, malingering, non-physiologic visual loss, factitious visual loss, psychogenic visual loss, hypochondriasis, and conversion disorder of vision).^{2–5} We will use the term medically unexplained vision loss throughout this manuscript as this is the term families have told us is most acceptable as it makes no assumptions about cause.

In children, MUVL is not uncommon. The reported prevalence ranges from 1 to 9%.^{6–8} The incidence of MUVL has been estimated at 1–1.75%.^{9,10} As in adults with MUVL¹¹ and other medically unexplained symptoms,¹² socio-economic factors may also contribute to MUVL in children.

All previous studies indicate that girls are more commonly affected than boys.^{9,13–15} The reported mean age at presentation ranges from 9.0 to 13.4 years, but younger children can also be affected.^{9,10,13–18} The most common complaints are deterioration of visual acuity, visual field defects, and double vision.^{5,9,14,15} In the majority of cases, both eyes are

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affected.^{9,13–15} Other symptoms are photopsia (perception of flashes of light that are usually brief and intermittent), perception of phosphenes (light perceptions of any colour or shape other than intermittent flashes that are not induced by light entering the eye), photophobia (light hypersensitivity), dyschromatopsia (altered perception of colours), amblyopia, voluntary nystagmus, accommodation weakness, ptosis, blepharospasm, and painful eyes.^{3,5,14,15,19} Some children have a history of previous eye diseases and treatment.^{13,20} MUVL in the presence of known eye diseases, and/or non-ocular conditions such as asthma, autoimmune diseases and accidental^{13,21} or surgical trauma is referred to as functional overlay.²⁰

Children with MUVL are more likely to also report other medically unexplained physical symptoms such as headaches and abdominal or limb pain.¹⁴ MUVL is also associated with factors similar to those underlying other medically unexplained physical symptoms. For example, 40–90%^{9,19,22} of children with MUVL also report psychological stressors such as family problems, problems at school, or bullying.^{10,19,23} High rates of mental health problems have been reported in adults with MUVL,¹⁴ and some research has indicated that young people with MUVL are more likely to report symptoms such as depression and attention deficit hyperactivity disorder.^{16,24–27} As with other medically unexplained symptoms, there are likely to be multiple interacting causal factors, and the presence of co-morbid mental health disorders does not suggest that symptoms are ‘all in the mind’. In other medically unexplained symptoms (eg, headache, stomach pains, and so on), as many as 30–50% of children have associated mental health disorders.²⁸ Screening for and detecting mental health problems in children with MUVL may facilitate access to appropriate services.^{2,4,14,15}

The rate of spontaneous resolution of MUVL in children has been reported to be high, particularly in studies with long follow-up data, ranging from 37% at 12 months¹⁰ to 100%⁹ (unknown duration of follow-up); the management of MUVL therefore often focuses on providing reassurance to the child and family that the visual prognosis is excellent.

There are no management recommendations for ophthalmologists, beyond the establishment of the diagnosis. To establish current practice and outcomes and to facilitate service planning and the development of future research projects, we carried out a retrospective observational study to describe incidence, clinical characteristics of patients, current diagnostic workup, and outcomes of MUVL in children.

Subjects and methods

This service evaluation had Trust approval (CA16/ONSP/91). A research fellow (MCD) collated

demographic and clinical data of consecutive patients younger than 16 years who presented to the children’s eye casualty at Moorfields Eye Hospital over a 12-month period and were diagnosed with MUVL or suspected MUVL. The research fellow reviewed clinical records at least 3 months after the initial presentation. All information was gathered from the clinical notes. To keep bias to a minimum, the same person collected data from all the files. We calculated the incidence using the number of ‘new patient’ attendances over the same period as denominator ($n = 2397$). Patients were included into the study if a diagnosis of ‘MUVL’ or ‘functional visual loss’ was documented in the medical notes and was not revised over subsequent clinic visits. We recorded any history of previous eye problems that had occurred at least 4 weeks before the presentation that led to a diagnosis of MUVL and could therefore be reasonably assumed to be unrelated. Children were considered as having fully recovered if they felt the eye problems had completely resolved and visual acuity was at least 0.1 logMAR in the initially affected eye. In cases where visual acuity at first presentation could not be determined in logMAR values (‘hand movements’ or ‘perception of light’), we did not quantify the change in vision between visits. The main outcome measures were the number of patients diagnosed with MUVL, the proportion of patients with a history of or present psychological problems, the recovery rate, and the improvement in visual acuity. All data were analysed using descriptive statistics. We adjusted denominators for missing data. To address loss to follow-up, the recovery rate was calculated separately for children with a follow-up of 3 months or less and for the subgroup of children who had a follow-up of 3 months or longer.

Results

Incidence

We identified 88 cases of suspected MUVL. Three children were subsequently found to have isolated optic disc atrophy, macular dystrophy, or optic neuropathy, confirmed by abnormal electrophysiological findings. These children were excluded from the analysis. Eighty-five cases were included in the analysis. We estimated the annual incidence in our setting to be 3.5% (95% confidence interval 2.85–4.35%). The number of children diagnosed with MUVL peaked during the winter months (Figure 1).

Patient characteristics

The median age at presentation was 9 years (IQR 7–12). Fifty-four patients were girls. The median number of

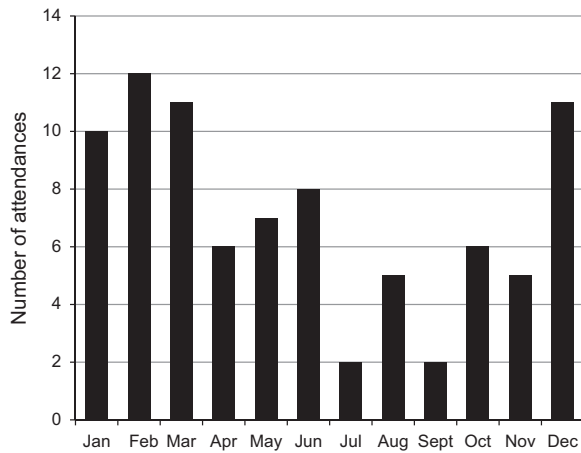


Figure 1 Seasonal variation of the number of children diagnosed with MUVL. Peak in the winter months.

appointments was 2 (IQR 1–3). Twenty-eight children only attended once. The median time from onset of symptoms until initial presentation was 1 week (IQR 0.14–2); the median duration of follow-up was 1.2 months (IQR 0–4.3) (Table 1).

Diagnostic workup and findings

There was considerable variability in diagnostic investigations (Table 1). Thirty-one per cent of all children were diagnosed with orthoptic abnormalities or refractive errors, and 12% showed abnormal visual field test results. Fifty-seven per cent had a previous history of contact with eye health professionals for glasses or surgical procedures.

None of the children seen during this period were referred for psychological assessment or intervention.

Patient history and presentation

Sixty-four per cent of all children had bilateral symptoms. Thirty-six per cent had a history of eye problems or ocular surgery. Forty-one per cent had glasses at first presentation. The most common complaints were deterioration of visual acuity (68%), painful eyes (24%), photopsia or perception of phosphenes (19%), and diplopia (19%). Complete loss of vision (13%), photophobia (9%), visual field loss (7%), and swollen lids (7%) were less common.

Ocular symptoms were associated with non-ocular symptoms in 35% of all cases, headache being the most common complaint (93%).

Forty-eight per cent of all children had non-ocular health problems such as allergies, asthma, and hypothyroidism. Rare diagnoses were complex regional pain syndrome, lactose intolerance, Marfan syndrome,

Table 1 Incidence, clinical workup, and demographical and clinical characteristics of children diagnosed with MUVL

Number of children diagnosed with MUVL	85	
Age (years)	Median	IQR
	9	7–12
Number of appointments	2	1–3
Duration of follow-up (days)	35	0–130
Ratio (female : male)	1.7	
<i>Investigations</i>	n	%
Orthoptic assessment	57	65
Refraction	47	53
Perimetry	24	27
Visual electrodiagnostics	21	24
Optical coherence tomography	13	15
Referral for paediatric assessment	12	14
Neuroimaging	5	6
<i>Psychological characteristics</i>		
History of psychiatric problems	3	4
External stressors	24	28
Clinical signs of depression	1	1
Full recovery at last follow-up	21	25
Within 3 months	11	13
After at least 3 months follow-up	10	35
Incidence	3.50%	

migraine, and thalassaemia. A brief behavioural and emotional symptom history, and a history of previous clinical service use were taken as is usual in any paediatric consultation. Thirty-three per cent of all children had a history of psychiatric disorders or showed signs of psychiatric disorder at the time of first presentation. One child currently reported current clinical levels of depression (under psychiatric care), three children had a history of psychiatric problems, but no longer showed symptoms at the time of presentation, and 28% reported stressful life events. Twenty-four per cent reported recent injuries.

Clinical course and resolution of symptoms

At last follow-up, 21 children (25%) had fully and 12 (14%) had partially recovered (resolution rate at 3 months after first presentation: 13% and resolution rate after at least 3 months of follow-up: 34%). The median improvement in best-corrected visual acuity (worse affected eye) was 0.22 logMAR (IQR 0.06–0.43). When tested for visual acuity, four children claimed not to be able to see anything or to perceive light or hand movements only; we excluded these from the analysis. Three of these children had normal visual acuities at the

last follow-up. One child did not report any clinically significant improvement of visual acuity.

Discussion

Our principal finding of a 3.5% incidence of MUVL in children and young people attending a specialist ophthalmological hospital is two to three times higher than previously reported.^{10,11} Our study also challenges the commonly held belief that—in children—MUVL has a high rate of spontaneous resolution. We report here that 3 months after presentation, 87% of those children who had at least 3 months of follow-up still experienced vision problems.

The high incidence of MUVL in this study may be explained in part by the setting, a walk-in clinic in a specialist ophthalmological hospital providing tertiary care level workup for patients who often have not consulted their general practitioner or local optometrist before attending our service. We observed that a high proportion of children with MUVL had previous experience with eye care providers; this may have raised their awareness of the possibility of having eye problems and direct access to eye care providers. The number of children diagnosed with MUVL peaked during the winter months, indicating possible seasonal variation. However, our sample size is small and limited to one calendar year only. In addition, we did not systematically ask children about any seasonal stressors/relieving factors (eg, school examinations/school holidays). Further research is required to establish any seasonal variation in the incidence of MUVL.

MUVL may have commonalities with other medically unexplained symptoms such as headaches, abdominal pain, and non-epileptic seizures, including co-morbidity with common mental health disorders including anxiety, depression, and behavioural problems.²⁸ Currently, there is little known about the mental health of young people with MUVL, and there is no routine screening, established referral pathways or guidelines for the detection and management of mental health difficulties associated with MUVL. It has been suggested that an absence of mental health disorders may be associated with faster resolution of symptoms,²⁴ though this finding is controversial.^{14,19} Though psychiatric consultation has not yet been shown to improve final visual outcome,⁷ patients may benefit from addressing psychological issues.¹³ Cognitive behavioural and whole-system approaches to the management of other medically unexplained symptoms and associated mental health difficulties are successful for the management for both adult patients and children and young people.^{25–27,29,30} Screening for psychiatric co-morbidity in MUVL in young people will allow early detection of emotional and behavioural problems, and

facilitate access to evidence-based psychological therapies. Therefore, a comprehensive multidisciplinary assessment of these children is likely to include, in addition to the ophthalmological and medical history, a mental health review, family history, and social and educational history.

The low rate of recovery in this study compared with other publications (93¹⁴–100%⁹) may in part be explained by the lack of a standardised definition of ‘complete resolution’ and by the relatively short follow-up in our study. Ophthalmologists are often satisfied when good vision can be demonstrated, and limit management to providing a ‘strong dose of reassurance’ that symptoms will resolve.^{7–9,13} Some discuss psychological aspects with the family and the general practitioner.¹⁵ Few refer children for neuropsychological evaluation.⁵ In other medically unexplained conditions, the presence of an unrecognised co-morbid mental health problem can impact negatively on the symptom trajectory.^{28,31} In recent years, there has been an emphasis on integrating mental and physical healthcare, therefore it is necessary to ensure that young people with MUVL are referred to appropriate evidence-based services for treatment if a psychiatric co-morbidity is identified.

Limitations of our work include data collection at a single site in a highly urbanised area and the relatively short follow-up duration. The present study does not allow conclusions on the long-term course of MUVL. Longitudinal studies with a longer follow-up duration could provide valuable information on the fluctuation of symptoms and the likelihood of relapses, and/or the simultaneous or delayed manifestation of other types of medically unexplained symptoms. However, our setting caters for a multi-ethnic urban population and we expect our findings could be replicated in similar settings. A further limitation is the current lack of a ‘positive diagnosis’ and a lack of consensus in terminology. A recent qualitative study of non-epileptic seizures highlighted the importance of families and young people having ownership over the terminology used to describe their condition,^{32,33} and the field is likely to be advanced through qualitative studies to explore and examine the experiences of young people with MUVL.

To achieve optimum and rapid recovery in paediatric MUVL, it is likely that integrated ophthalmological and mental health assessment and treatment will be needed. The low rate of full recovery of MUVL with ophthalmological approaches alone suggests that additional interventions may be needed. Identifying, understanding, and alleviating psychosocial stressors may be important as they may be precipitants or causes of MUVL. In addition, establishing rates of psychiatric co-morbidity (eg, anxiety, depression, and so on) in these

children will improve understanding of mechanisms and identify additional treatment targets.

Summary

What was known before

- MUVL is a common diagnosis in children.
- MUVL may be associated with mental health problems.
- There are no management recommendations for ophthalmologists, beyond the establishment of the diagnosis.

What this study adds

- The incidence of MUVL is higher and the rate of recovery lower than previously reported.
- A significant proportion of children with MUVL may have psychological problems.
- Children with MUVL might profit from integrated ophthalmological and mental health assessment and treatment.

Conflict of interest

The authors declare no conflict of interest.

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