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Barriers to immediate corticosteroid treatment in suspected giant cell arteritis with visual symptoms: insights from a tertiary eye care unit

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Abstract

Background Visual symptoms in Giant cell arteritis (GCA) represent a sight-threatening condition; immediate treatment with systemic corticosteroids is important. Treatment delays may occur due to several issues such as diagnostic uncertainty, unfamiliarity with managing the condition or logistical medication issues. Current literature has not assessed local factors that might impact timely management of suspected GCA patients with visual features; we explored this and created an innovative infographic to enhance current practice.

Methods Following an index case, we formed a multi-disciplinary working group to improve current practice. We started with an online questionnaire assessing the confidence and practice of our emergency eye care (EEC) team managing suspected GCA patients presenting with visual symptoms. Responses were collected over 4 weeks.

Results We obtained valid responses from 41 out of 53 EEC staff. Most respondents felt confident taking a history (mean self-rating 4.3/5, CI: 4.0-4.6) and knowing investigations for GCA with visual loss (mean 4.0/5, CI: 3.7–4.3). However, participants were less confident liaising with rheumatology colleagues out of hours (mean 2.7/5, CI: 2.2–3.2). While 37.5% ($n=15$) of respondents thought they knew the pharmacy team's working hours, only one person was able to specify these correctly. We used information from the survey to design a novel GCA infographic, incorporating British Society of Rheumatology (BSR) 2020 and European Alliance of Associations for Rheumatology (EULAR) 2018 guidelines. We displayed the infographic in EEC and provided teaching to EEC staff to address the issues that we found.

Conclusions This novel study has identified local factors that negatively impact immediate management of suspected GCA patients in EEC and designed an infographic to support clinical decision-making. Data from other centres and further evaluation of this approach is needed to assess its impact on practice.

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Keywords Giant cell arteritis, Visual loss, Emergency eye care, Corticosteroid delay, Multidisciplinary team, Clinical infographic

Background

Visual loss in Giant Cell Arteritis (GCA) patients is one of the more serious complications and can affect up to 20% of patients at presentation [1]. Early initiation of emergency corticosteroids in patients with visual symptoms and suspected Giant cell arteritis (GCA) is important to prevent permanent, irreversible vision loss. Furthermore, GCA can lead to ischaemic stroke if left untreated although this is uncommon [2]. The British Society for Rheumatology (BSR) guidelines state that suspected GCA is a medical emergency that should be treated immediately with high dose corticosteroids and the clinicians should follow relevant guidelines for prevention of coronary and other atherosclerotic vascular diseases in GCA patients [2].

Early recognition of GCA is important for all doctors including ophthalmologists, medico-legally. In the recent Rheumatology Getting it Right First Time (GIRFT) report [3], litigation costs related to 22 GCA cases exceeded £6,000,000 (2013–2018). The number of litigation claims was over 4 times higher in non-rheumatology specialties [3], highlighting the importance of appropriate urgent involvement of appropriate specialist teams and good quality education for all specialist teams where these patients can present. GIRFT in Ophthalmology does not include GCA, although emergency eye care (EEC) remains the primary point of contact for several patients with visual symptoms in GCA.

Diagnosis may be delayed for various reasons including healthcare staff not recognising the potential seriousness of symptoms, systems issues such as unclear referral pathways, and patient-related factors which may limit communication. A retrospective audit of 65 patients diagnosed with GCA found that there was significant delay in symptom recognition in patients with neuro-ophthalmic complications and the mean time from symptom onset to initiation of corticosteroids in these patients was 22 days [4]. The diagnosis of GCA is made more challenging by insidious and non-specific symptoms and normal inflammatory markers do not exclude GCA [5].

Therefore, it is essential for EEC staff to recognise the different ways in which GCA can affect the eye. Visual sequelae of GCA vary depending on the blood vessels affected [2]. The most common visual complication is anterior ischaemic optic neuropathy (AION) due to ischaemia of the posterior ciliary arteries and ophthalmic arteries [2]. AION can present with poor visual acuity as well as peripheral island and sector defects, mainly affecting the nasal and inferior field [6]. The optic discs may appear normal initially despite visual symptoms if the retrobulbar portion of the optic nerve is affected by ischaemia i.e. posterior ischaemic optic neuropathy (PION) [7], so careful assessment of optic nerve function is essential in addition to fundoscopy. In PION, the visual field defect is typically a scotoma, sometimes accompanied by additional peripheral defects [6]. Diplopia may result from ischaemia of cranial nerves supplying the extraocular muscles, following a brainstem stroke causing a skew deviation [5] and has also been hypothesised to result from muscle ischaemia [7]. Central, branch or cilioretinal artery occlusion, occipital lobe infarct, transient monocular visual loss, and photopsia have been also reported [5]. Charles Bonnet syndrome, a visual hallucination formed by visual cortex activities when there is lack of visual input from the eyes, may ensue when resultant visual loss is severe [5].

The new Giant Cell Arteritis Hospital Quality Standards provide a welcome reminder of the need for collaboration between rheumatology and ophthalmology colleagues to co-ordinate effective care [8]. Fast track pathways in the UK [9] and elsewhere [10] have shortened the time-to-diagnosis, by enabling rheumatologists to review patients within as little as one day [9]. Some departments have set up vascular ultrasound at the heart of a multidisciplinary fast track pathway with ultrasound and clinical assessment together on the same day or next working day [11]. Despite such initiations, we had an index case where a patient with suspected GCA with visual symptoms presented in EEC was not given the desired corticosteroid regime immediately and hence we realised that this was an issue within our EEC team. This led to this project aiming to address some of the local issues in emergency management of GCA.

The aims of this project were to assess and address the issues relating to emergency administration of corticosteroids in patients with visual symptoms and suspected GCA and to increase awareness of the different ways GCA can present to the EEC.

Methods

This study had 2 parts -the first was a questionnaire to understand the issues around management and the second part involved development of an intervention – infographic. The study was conducted in accordance with the Helsinki Declaration. Ethics approval was not required as per the Health Research Authority (HRA) tool in the UK. The study was approved by the governance committee in Oxford University Hospitals ophthalmology department as a quality improvement project in the department (Ref: 8073). We provided background information about

our project to all staff in EEC and clarified that participation in the online anonymous questionnaire was entirely voluntary. The questionnaire was designed to be anonymous, and no participant personal details were collected in this study. Participants were provided time and opportunity to ask questions. Implied consent was applicable in this study as per University of Oxford Research Ethics guidelines.

Following the index case, we set up a multi-disciplinary team including neuro-ophthalmologists, pharmacists and rheumatology colleagues to discuss the cases with delay in management of suspected GCA patients. We reviewed BSR [2] and European League against Rheumatism, now known as European Alliance of Associations for Rheumatology (EULAR) [12] guidelines and then did a full literature review. The details of literature review methods are available in supplementary material 1a. We identified 10 papers, of which 9 explored factors for diagnostic delay in GCA. They addressed consultation delay from patients' lack of awareness of urgency of their symptoms (n = 1), delay in recognition of symptoms and signs of GCA (n = 1), atypical presentations of GCA imposing challenges in making a diagnosis (n = 6), and lack of rapid access to specialist services resulting in diagnostic delay in primary care (n = 1). We did not find any studies that were specifically addressing the issues relating to immediate management in EEC.

We then devised a questionnaire to define gaps in current knowledge. The questionnaire was designed based on the methods outlined from Gehlbach [13] (supplementary material 1b). The questionnaire was administered online for EEC staff using Google Forms and comprised 7 questions (Fig. 1) inviting respondents to score their confidence from 1 (= not confident at all) to 5 (= very confident). Each question allowed respondents to make free text comments. We asked participants to describe their role in the EEC. Two further questions asked whether respondents knew the working hours of the pharmacy team, both in hours and out-of-hours and if so, to specify what these are. Doctors were also asked to specify how they would prescribe corticosteroids in the EEC, for example, by using electronic patient records (EPR).

We distributed the online questionnaire to EEC staff via email invitations from the working group and the EEC Sister with a reminder at 2 weeks. The final survey responses were analysed 4 weeks from the first day of the questionnaire distribution using Microsoft Excel. We calculated the mean, standard deviation, and confidence intervals. Responders' comments were classed as qualitative data and interpreted with thematic analysis.

Results

We surveyed 53 members of clinical staff, across all roles and grades, who work in the EEC for at least one regular session per week; we received responses from 41 staff (77%) in March 2023. Most survey respondents were doctors; 40% were nurses and allied health professionals (Table 1). Among 53 total EEC staff working in our department, 23 (43%) were permanent.

37 out of 41 respondents were confident with history taking and knowing which investigations were needed

I feel confident taking a history.

I feel confident liaising with rheumatology in hours.

I feel confident liaising with rheumatology out-of-hours.

I know how soon patients should be referred.

I feel confident knowing what investigations are needed for diagnostic assessment from the EEC.

I feel confident knowing what the treatment is.

For doctors, kindly specify how you would normally prescribe e.g. EPR, FP-10, ask GP, stat dose.

I feel confident giving advice about possible treatment-related complications.

I know the working hours of the Oxford Eye Hospital pharmacy team.

Please specify working hours of the pharmacy team if known.

I know how to contact the Oxford Eye Hospital pharmacy team out-of-hours.

Please specify working hours of the Oxford Eye Hospital pharmacy team out-of-hours if known.

It would be really helpful to know your role in the EEC please.

Fig. 1 Questionnaire assessing the confidence level and knowledge of managing GCA among EEC staff

Table 1 The roles of respondents in EEC

Role	Number of responses (Total number of staff)
Registrar/Fellow	21 (25)
Optometrist	2 (7)
Nurse	8 (9)
Health Care Assistant	3 (5)
General Practitioner	2 (2)
Consultant	2 (3)
Senior ophthalmic technician	2 (2)

Table 2 Survey responses

	Mean	Median	95% Confidence interval
I feel confident taking a history.	4.3	4	4.0-4.6
I feel confident liaising with rheumatology in hours.	3.9	4	3.5–4.3
I feel confident liaising with rheumatology out of hours.	2.7	3	2.2–3.2
I know how soon patients should be referred.	4	4	3.7–4.3
I feel confident knowing what EEC investigations are needed for diagnostic assessment.	4.3	4	4.0-4.5
I feel confident knowing what the treatment is.	3.9	4	3.5–4.1
I feel confident giving advice about possible treatment-related complications.	3.7	4	3.3–4.1

The mean and median scores of the level of agreement with each statement in the questionnaire on a scale of 1 to 5, 1 being strongly disagree and 5 being strongly agree

(Table 2). Both mean and median scores of confidence levels were 4 and above in all grades of clinicians (Supplementary Table 1). Participants were least confident liaising with rheumatology out of hours, as only eight out of forty respondents were confident with this and only over a half of respondents (21 out of 41) were confident in normal hours (Table 2). Apart from consultants and imaging technicians who are not involved in contacting rheumatology out of hours, and GPs, the mean confidence level was below 3 in all grades of clinicians (Supplementary Table 1).

There was much uncertainty regarding pharmacy opening hours. A little more than a third of the respondents (15 out of 40) said they knew pharmacy working hours but only three respondents specified these correctly for normal working hours and only one respondent knew the out-of-hours pharmacy availability. All consultants, nurses, and imaging technicians were aware of how to contact pharmacy out-of-hours whereas only 42.86% of registrars and fellows were aware of the information.

24 doctors specified how they would prescribe oral corticosteroids (CS) in the EEC. There was considerable variation in CS prescriptions. Half said they would prescribe a stat dose in EEC although they did not specify how they would prescribe this. 3 doctors said they would prescribe further doses on the Electronic Patient Record (EPR), one said EPR in hours and GP out-of-hours, two would prescribe it using the NHS Prescription (FP10) and the other two said they would use either EPR or FP10. Among the 12 doctors who did not specify they would prescribe oral corticosteroids as stat dose, 8 responded that they would prescribe it on EPR. One person said they would prescribe on FP10 and another would prescribe it on FP10 or EPR. Worryingly, one doctor said they would ask the GP to prescribe it.

The qualitative feedback on liaising with rheumatology team included:

> *Sometimes it is very difficult to get in touch with the rheumatology team during working hours.*

> *I would feel confident if able to get hold of them but recently it seems they have reduced their on-call availability.*

> *Not sure of contact details other than SpR via switch.*

Some allied health professionals and nurses expressed their belief that rheumatology liaison should be done by doctors.

Most respondents were confident knowing treatment (Table 2). Some commented they like to discuss with the rheumatology team first. Some reflective comments taken from the survey related to this included:

> *In theory yes but would only feel confident in conjunction with a rheumatologist.*

> *Yes, in straightforward cases. But for special cases (e.g. The patient who also has uncontrolled diabetes, who are steroid responders, or who is already on steroid etc.) I liaise with the appropriate specialty team for their guidance and opinion in the MDT [multidisciplinary team] approach.*

> *Treatment protocols are different: more oral than IV steroids*

Two allied health professionals mentioned that while they are aware of treatment, they felt prescribing corticosteroids should be done by a doctor. Unlike doctors, AHPs felt they were less confident with giving advice about treatment related side effects, with mean confidence level score being 3.5 in nurses, 2.5 in optometrists, and 1.67 in

HCAs while they were 4 and above in registrars/fellows, GPs, and consultants (Supplementary Table 1).

We performed a robust stakeholder engagement exercise following the results of the questionnaire including the pharmacy team, Clinical Director and Clinical Governance Lead and we also got input from the stroke and acute medical teams. We then designed an infographic based on the outcome of this exercise with the aim of streamlining the management of suspected GCA patients in EEC. Our infographic (Fig. 2) includes pharmacy and rheumatology contact details and highlighted the importance of giving a stat dose of oral corticosteroids in EEC. We sourced pictures for our infographic via Microsoft Word Online pictures, selecting only those with Creative Common licenses, supplemented by original photographs belonging to author VN, where required. Once this was finalised, we delivered a teaching session to EEC staff, disseminated the infographic in the weekly staff update and set up permanent poster displays in EEC consultation rooms. We advised clinicians to ensure patients with probable GCA are observed taking their first dose of corticosteroids before leaving the EEC. We included a prompt for staff to liaise with the patient's diabetic team for any patient with pre-existing diabetes, given their control could be adversely affected by high-dose oral corticosteroids.

A flow diagram of how to manage suspected GCA patients from initial presentation at triage to treatment was also included. The details of the applications of ophthalmic tests in the infographics can be found in supplementary material 2. VA: visual acuity, IOP: intraocular pressure, RAPD: relative pupillary afferent defect, OCT: ocular coherence tomography, RNFL: retinal nerve fibre layer, ONH: optic nerve head, FBC: full blood count, ESR: erythrocyte sedimentation rate, CRP: C-reactive protein, U&E: urea and electrolytes, LFT: liver function test.

Through an iterative process that underwent multiple revisions and feedback from the staff working in EEC, we revised the infographic to ensure that it provided the right information to staff and addressed any underlying uncertainties.

Discussion

This is the first study investigating the challenges in immediate management of suspected GCA in the eye department. We found significant issues with understanding of local processes all of which would contribute to delay in administration of corticosteroids in suspected GCA patients. Given the risks (of permanent visual loss), impact on quality of life of people affected by this and associated litigation, this is an important finding and needs introspection from all major ophthalmology units. We hope to have mitigated that through the production of the infographic; this will need formal evaluation in due course. There is, of course, a significant turnaround among EEC staff, and frequently rotating staff present educational challenges to trainers, and this may adversely affect patient safety [14]. These risks can be substantially mitigated if robust systems are in place. Our survey response rate was high, and all EEC staff groups were represented. Suspected GCA with visual symptoms forms a small minority of patients coming to EEC, we estimate this to be around 1–2% of EEC patients presenting in our unit, although this may vary with units with different patient demographics and regional services. However, early management is critical to improving visual outcomes [9]. The 2020 BSR guidelines for GCA recommend immediate treatment with corticosteroids when there is strong clinical suspicion of GCA before waiting for the investigation results [2]. This highlights the importance of immediate treatment as in practice, same day temporal artery ultrasound or temporal artery biopsy is difficult and organ damage in GCA is time sensitive. The standard pathway for patients with visual symptoms is an urgent presentation to EEC, yet there are no specific ophthalmology guidelines and there remains lack of clarity around the processes in place for training of staff dealing with these patients. GIRFT for Ophthalmology need to consider inclusion of GCA with visual involvement in their metrics.

Whilst current literature mainly focused on the delay in treatment due to non-specific symptoms of GCA, we additionally identified that processes for dispensing corticosteroids have an important bearing on outcomes in GCA. The current GCA guidelines – both 2020 BSR and 2018 EULAR suggest considering starting intravenous methylprednisolone 250 mg to 1 g daily for up to three consecutive days followed by tapering to oral prednisolone for patients with acute vision loss or GCA related visual symptoms [2, 12]. If intravenous methylprednisolone administration is not possible, high dose oral prednisolone 60-100 mg per day should be given without delay as an alternative for up to three consecutive days [2]. Despite several studies over many years, there is lack of positive trial data for supporting IV Methyl Prednisolone over oral glucocorticoids. Two recent large studies have not reported differences in visual outcomes between intravenous Methyl Prednisolone and oral glucocorticoids [15, 16]. Furthermore, there is increased risk of complications such as diabetes in patients treated with IV Methyl Prednisolone within 12 months [15]. Traditionally, our practice has been to treat with oral prednisolone, intravenous methylprednisolone is sometimes used in refractory cases in liaison with the rheumatology team.

The disappointing lack of awareness about how to administer the first dose of CS represents a patient safety risk and potential worsening of visual outcomes. We had also identified variations in practice which are hopefully

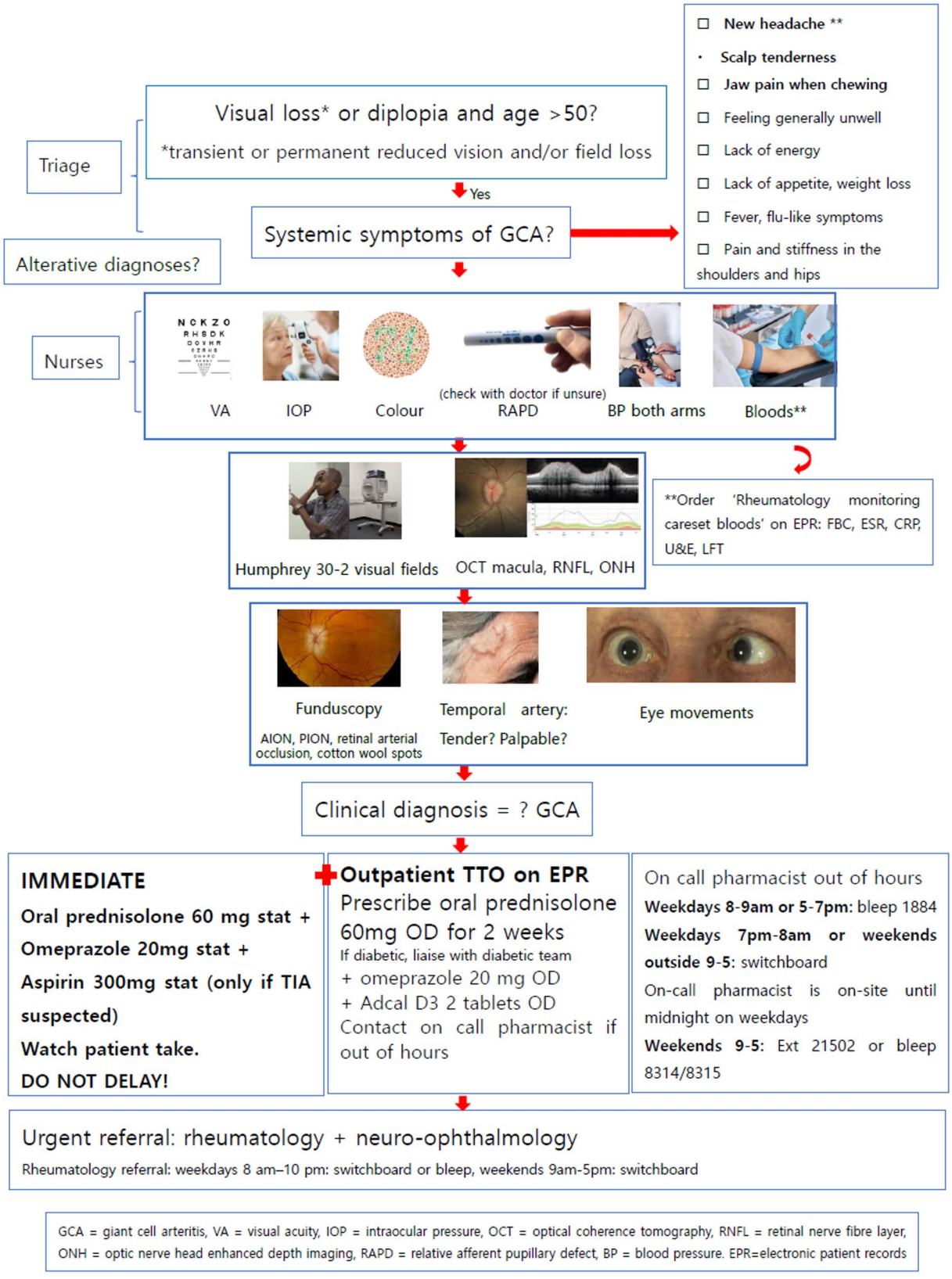

Fig. 2 GCA infographic

ameliorated by the infographic and the informal feedback on the infographic has been very positive. As GCA is an emergency condition, it would not be appropriate to ask patients to liaise with GPs as this would result in unacceptable delay, more so if the patient was seen out of hours. If FP10 prescriptions are used, patients must be given clear advice about how to get the emergency prescription cashed and follow on instructions. This delay increases the risks of permanent visual loss and reduced recovery from visual loss and imperils losing the gains from setting up fast track pathways for GCA [9]. Ophthalmology GIRFT should also include a section about the management of suspected GCA in the EEC as significant proportion of patients with visual symptoms will present to EEC and litigation costs to Ophthalmology services are much bigger than other departments.

Our novel infographic has increased awareness of pharmacy opening times and contact details among EEC doctors. This approach follows the GIRFT report which recommends implementing BSR GCA guidelines in each hospital to improve efficiency of managing suspected GCA patients [3]. Our pharmacy team has highlighted the importance of adequate corticosteroid supplies to be given to patients to facilitate uninterrupted corticosteroid treatment until more definitive investigations and firmer management plans can be put in place. Furthermore, we have advised clinicians to ensure patients take oral corticosteroids if starting oral treatment before they leave EEC to ensure the first dose of corticosteroids is given in a timely manner.

The 2020 BSR guidelines do not recommend prescribing antiplatelets or anticoagulants routinely for suspected GCA cases due to insufficient evidence from RCTs related to this topic although recommends following the guidelines on secondary prevention of cardiovascular diseases [2]. Aspirin is routinely recommended for management of transient ischemic attacks (TIA) and is part of the hospital guidelines for management of TIA [17]. The 2021 American College of Rheumatology/Vasculitis Foundation Guideline recommends aspirin for patients with reduced blood flow of the vertebral or carotid arteries [18]. The risk of aspirin in patients already on high-dose systemic corticosteroids is gastrointestinal bleeding, although mitigated with the use of proton pump inhibitors such as Omeprazole [19]. In patients with a stroke, aspirin should not be given until bleeding has been ruled out, these patients do not usually present to the EED, they would usually be admitted through Accident & Emergency department or medical take. The risks and benefits should be considered in individual cases in conjunction with advice from the medical team where required.

Our infographic was sent to all EEC staff to increase the awareness of emergency management of visual loss with GCA. With increasing roles for allied health care professionals in the EEC, it is important that everyone involved in the care of GCA patients knows how GCA patients should be managed [20]. Following feedback requesting clarity on the role of different clinician team members for each stage of management, we included this. Our infographic layout was designed to streamline triage as GCA bloods can be taken before patients are seen by EEC clinicians, to save time waiting for results.

Our survey results revealed the importance of helping new staff understand the referral system and the importance of urgent treatment plans to be instituted to minimise delay. This principle could also apply to other conditions such as optic neuritis. We do not believe that the issues we have identified are unique to us, they are likely to be prevalent in several other institutions. Similar studies or quality improvement projects need to be done across other hospitals and Trusts to understand local issues and address these. Our infographic could be adapted to standardise patient care across different Trusts, as recommended by the Carter report 2016 [21]. Whilst some units have clear local guidelines for emergency administration of corticosteroids, we have come across several examples from other units where there is less clarity on what should be done in EECs up and down the country. We believe that this type of intervention is likely to be beneficial for several EECs and will lead to greater quality assurance for patients with suspected GCA, thereby improving patient outcomes and reducing litigation costs to the NHS.

Our study has several limitations; questionnaires relating to confidence do not necessarily reflect competence. However, there is currently no validated tool for assessing competence for assessment and management of GCA with visual symptoms. Similar approaches have been used in studies where confidence level was used to assess the junior doctor induction programme; the need for more objective measure using patient safety data have been suggested [14]. Ongoing audit, reviewing reasons for any CS treatment delay in suspected GCA patients with visual symptoms is needed to ensure safe care is being delivered. While our infographic is based on the most recent national and international guidelines, this is not yet validated. We are expecting that majority of patients with suspected GCA will not have GCA and in other series, the proportion of people with definite GCA has been around 30 to 40% [11]. We intend to audit the patients who fulfil the criteria of being assessed under this algorithm and that is the next planned step. An approval for this audit has already been obtained. We would welcome collaboration from colleagues wishing to do so.

Conclusions

In conclusion, our study has identified practical gaps in the emergency management of suspected GCA in EEC and highlighted a lack of awareness of local hospital systems. This is an important training issue and must be addressed through education at induction and regular refresher sessions for staff. Our novel infographic has helped to reduce this information gap and holds promise in reducing delays in administering corticosteroids to patients presenting with suspected GCA. GIRFT Ophthalmology need to consider including a section on this.

Abbreviations

GCA	Giant cell arteritis
EEC	Emergency Eye Care
CS	Corticosteroids
BSR	British Society of Rheumatology
EULAR	European Alliance of Associations for Rheumatology
EPR	Electronic Patient Record
FP10	NHS prescriptions
MDT	Multidisciplinary team
GIRFT	Getting it Right First Time
AION	Anterior ischaemic optic neuropathy
PION	Posterior ischaemic optic neuropathy

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Supplementary Material 4

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Author contributions

Conception and study design: SD, VN, WYM; Data acquisition: WYM, VN; data analysis and interpretation: WYM, VN, SD; developing the infographic: WYM, SH, SD, VN; writing a draft manuscript: WYM; manuscript revision: WYM, SH, LT, SD, VN, manuscript review and approval for submission: WYM, SH, LT, SD, VN.

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Data availability

All data generated or analysed during this study are included in this published article.

Declarations

Ethics approval and consent to participate

The study was conducted in accordance with the Helsinki Declaration. Ethics approval was not required as per the Health Research Authority (HRA) tool in the UK. The study was approved by the governance committee in Oxford University Hospitals ophthalmology department as quality improvement project in the department (ref 8073). We provided the information about our project to all staff in EEC and participation in the online questionnaire was entirely voluntary. The questionnaire was designed to be anonymous, and no participant personal details were collected. Only the participants who consented to anonymised survey participated in this study. Implied consent was applicable in this study as per University of Oxford Research Ethics guideline: https://researchsupport.admin.ox.ac.uk/governance/ethics/resources/consent.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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