NETIMIS

CASE STUDY

The National Standard for Giant Cell Arteritis Diagnosis and Management

Client: The TARGET Consortium

Overview

This case study has been completed as part of a University of Leeds undergraduate student project in collaboration with The MRC TARGET Consortium and X-Lab Ltd. A simulation software, NETIMIS, has been used to simulate and model the giant cell arteritis (GCA) patient c are pathway from clinical suspicion through to a clinical diagnosis. The TARGET (Treatment According to Response in Giant Cell Arteritis) Consortium is the client for this project which aimed to explore opportunities within the NHS for improving the early diagnostic pathway as part of routine clinical practice.

About this Study

The aim of this case study is to showcase a series of models that were created to represent the patient flow of patients with suspected GCA. By understanding the challenges involved with the current pathway, potential improvements can be sought out to create hypothetical future pathways that deliver more effective diagnosis. In order to further validate the work conducted, an investigation into the national pathways within the UK for GCA diagnosis and management took place and the outcomes of this investigation have been included in this case study.

Challenges

At the moment, there is no independent diagnosis for GCA and this process relies on the ability of the healthcare provider to identify the symptoms described by the patient may be GCA. This decision will result in the patient to undergo a series of examinations by different clinical teams and diagnostic tests before a firm diagnosis, positive/negative, for GCA can be determined. The intention is to draw out the NICE pathway to allow for the visualisation of the current GCA pathway.

How NETIMIS Helped

NETIMIS has been used to draw out the NICE pathway to allow for the visualisation of the current GCA pathway. Although the processes described by NICE are clear to follow, by creating models in NETIMIS helped better comprehend the flow the patients. These models can be used by viewers and can be populated with real data to enhance the accuracy of the flow, and conduct analysis on the outcomes produced. This would allow different hospitals to simulate different models to determine those that are the most efficient and cost effective locally.

The National Guidelines for GCA

The pathways described in this document have been based on the guidelines provided by the National Institute for Health and Care Excellence (NICE). NICE has measures and goals in place to deliver guidance in delivering effective patient care. These measures, stated in the Clinical Knowledge Summaries (CKS) described by NICE[1] , aim to identify patients with suspected GCA and to make referrals for temporal biopsies appropriately and in a timely manner. The patients' symptoms should be controlled and frequently monitored and the risks of complications, like visual loss, should be mitigated. Long-term steroid treatment has many risks and side effects that should be monitored and minimised where possible. In doing so, the patients' independence, quality of life and mobility can be maintained.
The steps described below have been broken down into:

- **Suspicion of GCA**
- **Diagnosis**
- **Initial Management**
- **On-going management**

[1] The information presented on the next page has been gathered from NICE, (2014), Clinical Knowledge Summaries – Giant Cell Arteritis. Available online at: *https://cks.nice.org.uk/giant-cell-arteritis#!diagnosissub:1 [Last Accessed: 14/04/2018]*

The Steps

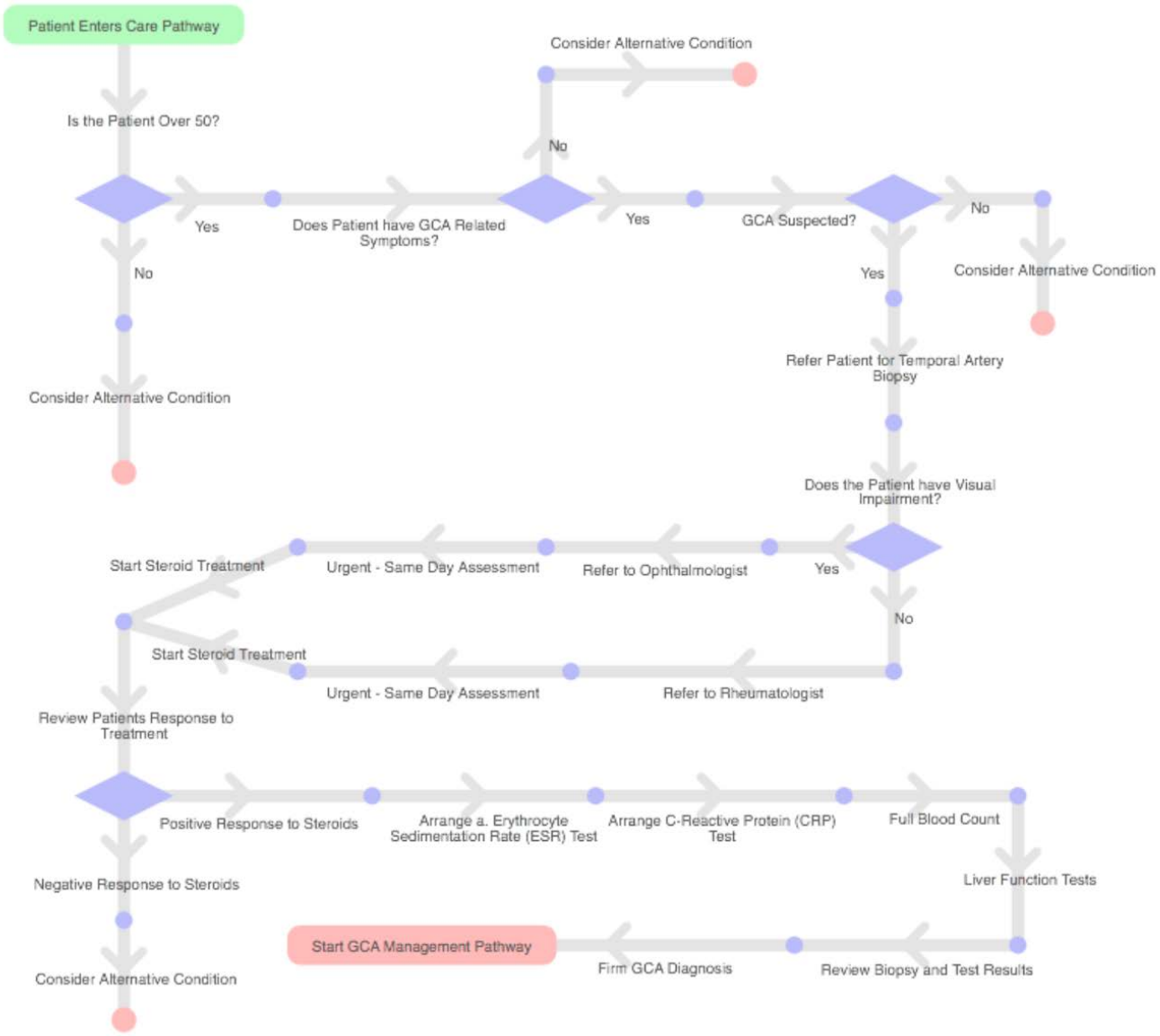
Steps when GCA is suspected:

1. GCA can be suspected if the patient is over 50 years old *and* displays the following symptoms:
    - Headache in the temple area
    - Abnormality in the temporal artery and these could be tenderness and thickening of the artery leading to a reduction in the pulse. This symptom is present in 45%-75% of patients who have confirmed GCA (NICE, 2014).
2. Other symptoms that could lead to suspected GCA include:
    - Systemic symptoms such as fatigue, fever, weight loss, poor appetite and depression. These symptoms affect the majority of patients with GCA.
    - Symptoms linked to polymyalgia rheumatic, as patients with this disease may also develop GCA.
    - Tenderness of the scalp (approximately 50% of patients with GCA have this symptom (NICE, 2014))
    - Jaw pain, affecting 50% of patients and this will lead to them feeling pain in the jaw muscles when chewing that is relieved by rest and this may also affect their tongue, muscles used for swallowing and arm claudication. Neurological features affecting approximately 30% of patients.
    - Visual impairment, this could be partial or complete vision loss in one, or both eyes. This symptom effects 20% of patients. The effects of visual loss are permanent and cannot be reversed.
    - Neurological features affecting approximately 30% of patients.
    - Peripheral arthritis and swelling in the hands, wrists, feet and ankles (this is uncommon)

Within the NETIMIS model, the patient demographics, their route of entry into the care pathway and their symptoms have been categorised like below:

Diagnosis of GCA

1. Refer all patients with suspected GCA to undergo a temporal artery biopsy. Positive results will confirm diagnosis, *but* a negative result does not rule out diagnosis
    - If patient displays visual loss, then refer to ophthalmologist for same day urgent assessment and prescribe 60mg prednisolone.
    - If patient does not display visual loss, then refer for urgent same day specialist assessment, usually rheumatology and prescribe 40mg prednisolone
2. Start oral steroids immediately whilst waiting for patient to undergo biopsy.
3. If patient's response to oral steroids is not positive (after 48hrs) then consider alternative conditions. If appropriate, arrange examinations to exclude other conditions.
4. Arrange the following tests and examinations, for a firm diagnosis alongside the biopsy results, Blood tests are done at the initial point of assessments/referrals:
    - Erythrocyte Sedimentation Rate (ESR), to establish if it is above 50mm/hr and approximately 20% of patients will display an elevated rate.
    - C-Reactive Protein (CRP) will be elevated amongst patients with GCA
    - Full blood count as patients with GCA will have an elevated platelet count.
    - Liver function tests as approximately 33.3% of patients will have elevated alkaline phosphatase.



Model available from:

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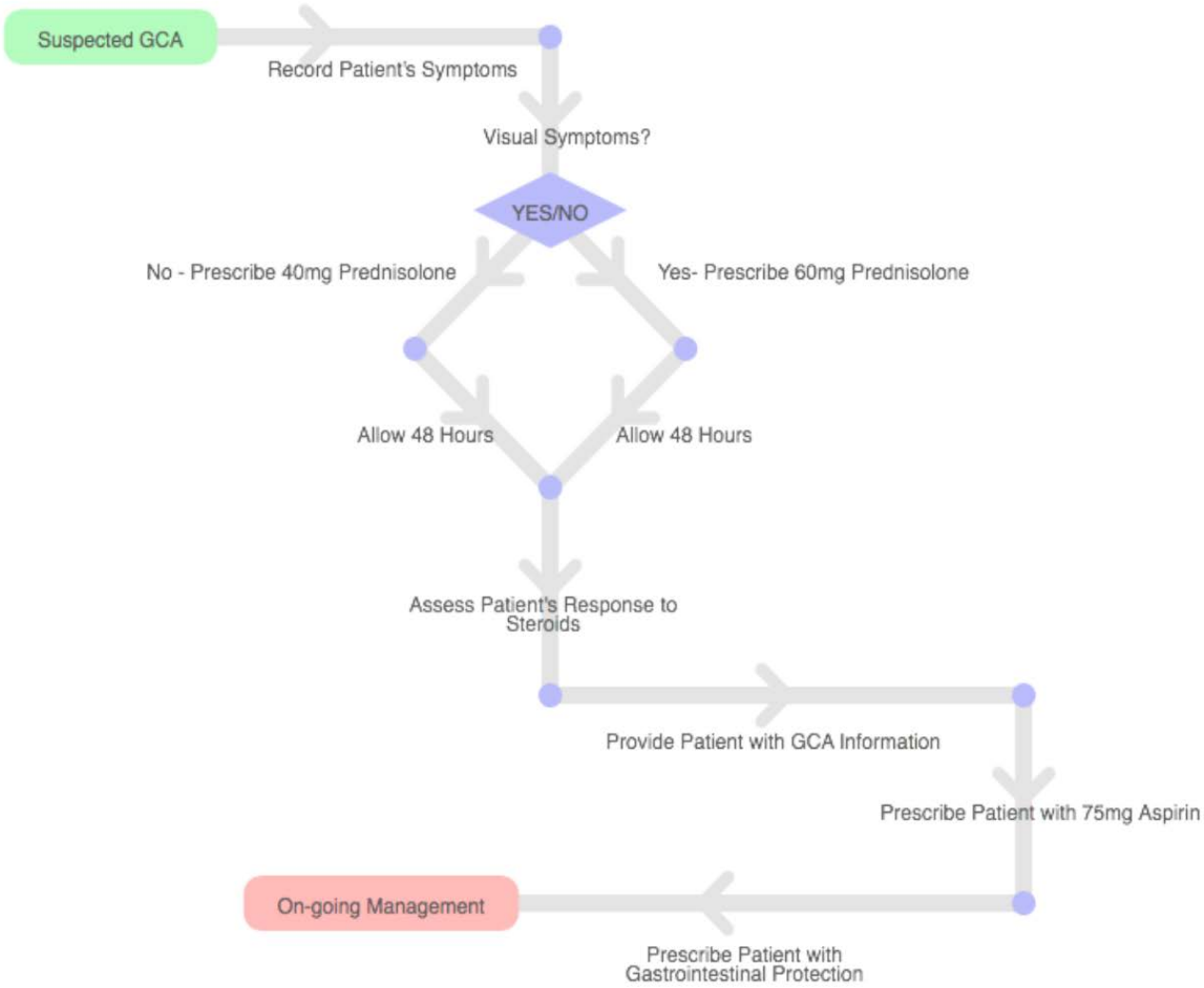
Initial Management

1. Record patients' symptoms (both before and after treatment to determine patient's response to treatment).
2. Prescribe oral steroids
    - If patient displays visual impairment symptoms, then refer to ophthalmologist and prescribe one-off dosage of 60mg Prednisolone.
    - If patient does not display visual symptoms, then prescribe between 40-60mg Prednisolone.
3. Assess the patient's response to steroid treatment within 48 hours.
4. Ensure patient is provided with relevant information and advise them to:
    - Seek immediate urgent care attention if any visual impairment symptoms emerge
    - In the case of a positive diagnosis, steroid treatment will continue for 1-2 years, and a lower dosage may be required after the 2 years
    - Relapses may occur when dosage of steroids are reduced
    - Regular follow-ups are necessary for monitoring patients' wellbeing and response to treatment
5. 75mg of Aspirin should be prescribed and taken daily by the patient. (usually recommended for patients with ischaemic features).
6. Patients should also be given gastrointestinal protection.



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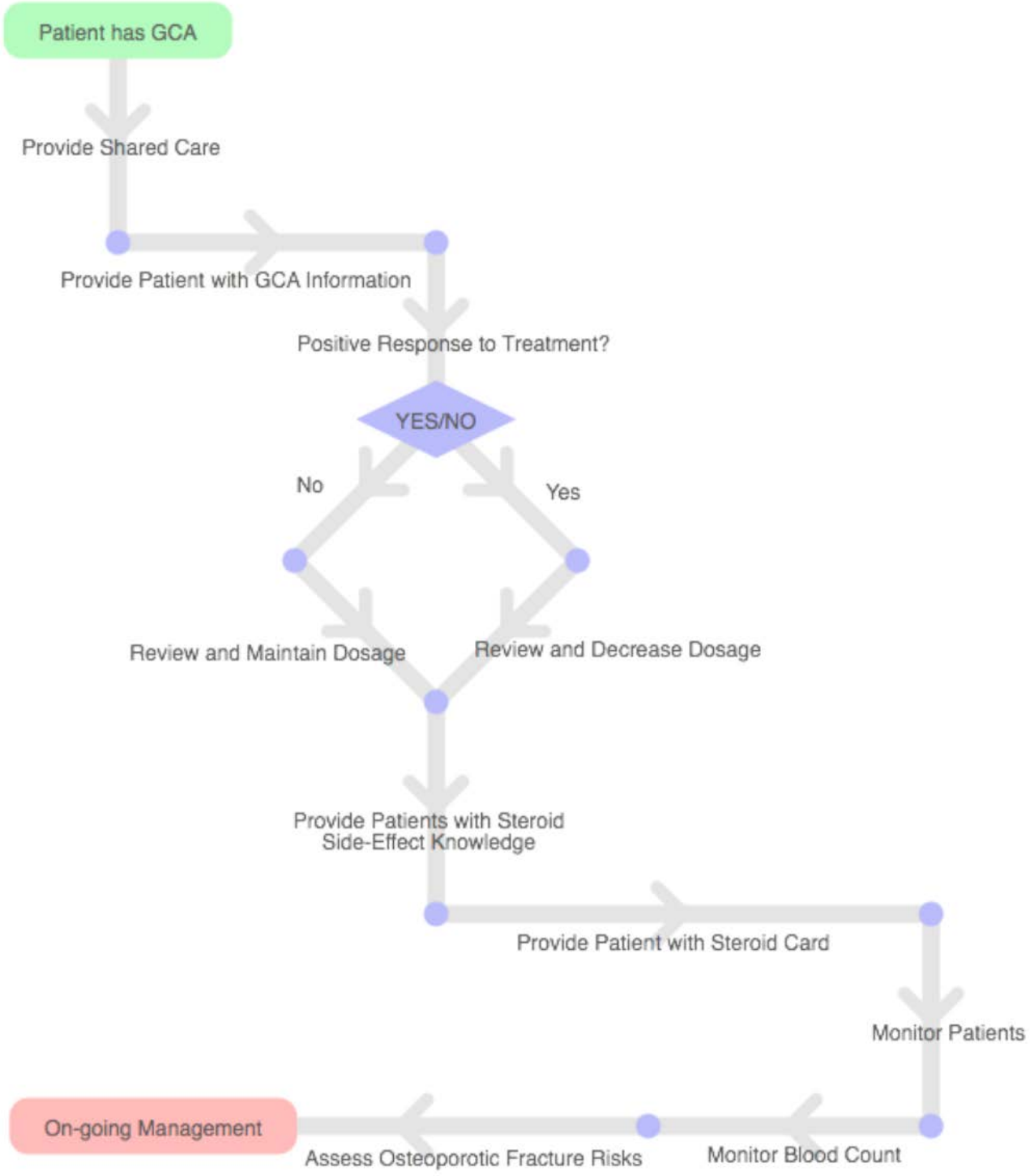
On-going Management

1. Provide shared care, between primary care, i.e. GP, and a specialist, i.e. rheumatologist.
2. Patient should be provided with information on GCA, such as booklets, and be advised to join a GCA support group.
3. If patient's response to steroid treatment is positive, and their symptoms are controlled, then the dosage of steroids can be decreased. This should be done on a patient by patient basis, and the dosage should be tailored to each individual based on their diagnosis.
4. Each patient should be provided with a blue steroid card and they should be informed on the side effects they may experience as a result of taking them. However, they should also be advised not to stop taking their medication unless directed to do so by a specialist. Patients should also avoid contact with people who may have shingles, chicken pox or measles as they would be prone to being contaminated with diseases such as these.
5. Patients should be monitored frequently –
    - Within the first year of diagnosis, weekly follow-ups may be required whilst the patient is on a high dosage of steroids. If steroid intake is reduced within this time a routine check should be carried out 1 week after dosage change, and this should be done every 3 months
    - After the first year of treatment, each patient should be seen every 3-6 months, but more frequently should they have a relapse
6. Every 3 months the patients' bloods should be checked, and their ESR/CRP counts should be assessed.
7. Each patient's osteoporotic fracture risks should be assessed and managed throughout treatment.
8. The patients should be monitored for disease activity and steroid toxicity throughout.



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