A survey of the use of artificial nutrition in patients with hypermobility disorders in selected intestinal failure units in England to establish the extent of use of artificial nutrition and rates of complications associated with the use of artificial nutrition in this group of patients.

Subtitle: A survey of the use of artificial nutrition in patients with joint hypermobility

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Background: Patients with hypermobile disorder (HD) were recognised as having higher rates of gastro-intestinal (GI) symptoms compared to healthy controls, and since then, further studies have reported the prevalence of at least one GI symptom in 30-96% of patients with hypermobile disorders. GI symptoms in patients with HD appear to be due to functional disorders, which are disorders where symptoms are experienced in the presence of usually normal investigations due to disordered communication between the brain and gut, the cause of which is multifactorial. With the increase in prevalence of HD and the prominence of GI symptoms, many of these patients face nutritional issues due to their symptoms. Visceral hypersensitivity has been demonstrated in this group of patients and is often the reason for the increasing prevalence of the use of parenteral nutrition(PN) or intravenous fluids. These are high risk strategies and cannot usually be justified unless in specific circumstances where the risks and benefits have been thoroughly evaluated The true prevalence of the use of parenteral nutrition in HD patients is unknown and we have no data in the literature assessing the prevalence within England, let alone elsewhere in the world, nor do we have any data looking at outcomes in these patients. There is an increasing concern that the outcomes for these patients with hypermobile disorders on parenteral nutrition and IV fluids are poor, with significant complications related to the underlying hypermobility disorder, complications from unwarranted interventions and complications from polypharmacy. These patients consume significant healthcare resources when faced with these complications. More worrying is the anecdotally noted detrimental effects on their quality of life and adverse health outcomes.

Rationale : There is no evidence to support or refute this concern however, and it is not clear if this impression is well founded or not. Therefore, understanding this group of patients with HD on PN/intravenous fluids is a necessary first step towards a more evidence based approach in the diagnosis and management of these patients. This will also be a step towards understanding the gaps in care processes for these patients and also in understanding means of reducing iatrogenic harm and optimising healthcare.

Objective and scope: This study therefore aims to survey a selected group of intestinal failure units in England, describing the proportion of the caseload that HD patients make up, indications for parenteral nutrition, any complications as well as comorbidities, interventions and medications used over the past 10 years. The research questions are: (1) What is the proportion of patients with HD cared for by these IF units in England? (2) What are the indications for parenteral nutrition in patients with HD cared for by these IF units in England? (3) What complications do patients with HD in intestinal failure units cared for by these IF units in England suffer with in relation to their parenteral nutrition and their HD?(4) What comorbidities do patients with HD cared for by these IF units in England suffer with that impact diagnosis and management? (5) What interventions do patients with HD cared for by these IF units in England undergo? (6) What medications do patients with HD cared for by these IF units in England get prescribed? (7) What is the healthcare burden in this group of patients?

Planned activities & deliverables

- The data collected is retrospective, as the aim is to achieve a snapshot of all patients with HD on parenteral nutrition with a description of their journey to this point in time
- Data will be collected and amalgamated in a standardised excel sheet. Patient's data will be anonymised.
- This study has been submitted and approved by the main research and development department (Chief investigator: Dr G Amarasinghe, London North West University Healthcare NHS Trust) and currently awaiting approval by the local research and development department from the participating hospitals (Sheffield Teaching Hospitals Trust, Salford Royal NHS Foundation Trust, University College London Hospitals NHS Foundation Trust, Barts Health NHS trust London, Sheffield Children's Hospital NHS Foundation Trust, Leeds Teaching Hospitals NHS Foundation Trust and Cambridge University Hospitals NHS Foundation Trust.

What achievements are possible in the next 12 and 24 months?

- Collection/data analysis in 12 months
- Publication in 24 months

Resources & enablers

Financial needs for:

- Research assistant to help with data handling/entry and clean up
- Statistician to help with data analysis
- The investigators involved have no financial support for this study

What factors will make it successful?

- All participating sites are engaged to ensure the success of this study
- This would be the first study to look into the use of parenteral nutrition/fluids in this group of patients and to assess if there are potential iatrogenic harm from this

Results/outcomes & expected impact

How will the findings be implemented?

This study will be submitted and with an aim to be published in a peer review paper

How will this project advance patient care / contribute to optimal nutritional care?

This project will provide data that would provide further information about the use PN/Home IV fluids in this group of patients. It would also provide more informative data on the outcome of this patients including complications, investigations and polypharmacy used. This survey will also serve as a baseline for UK wide and global studies which do not exist at present. There are no guidelines globally for the diagnosis, management and avoidance of harm in this group of patients. The data in this study will inform such evidence based guidelines in the future.

What makes the project innovative?

There is no study done look at the prevalence and harm of parenteral nutrition/fluids in this group of patient. So the research questions mentioned above needs to be answered and to give further clarity on how to manage this group of patient

Will the project be likely to influence national nutrition policy?

Yes

Is the project transferable to other settings / countries?

Yes

√ **Please tick to confirm the PEN letter of endorsement is attached. Incomplete submissions will not be considered.**

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