From Assessment to Treatment: 60 minutes Journey

Emergency management of children with inherited metabolic diseases

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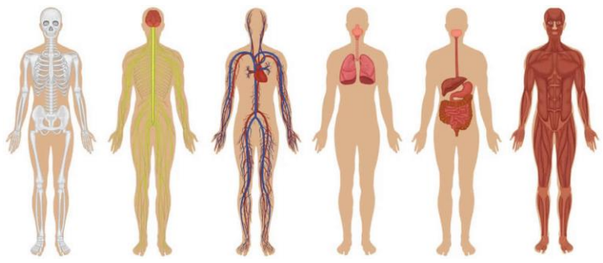
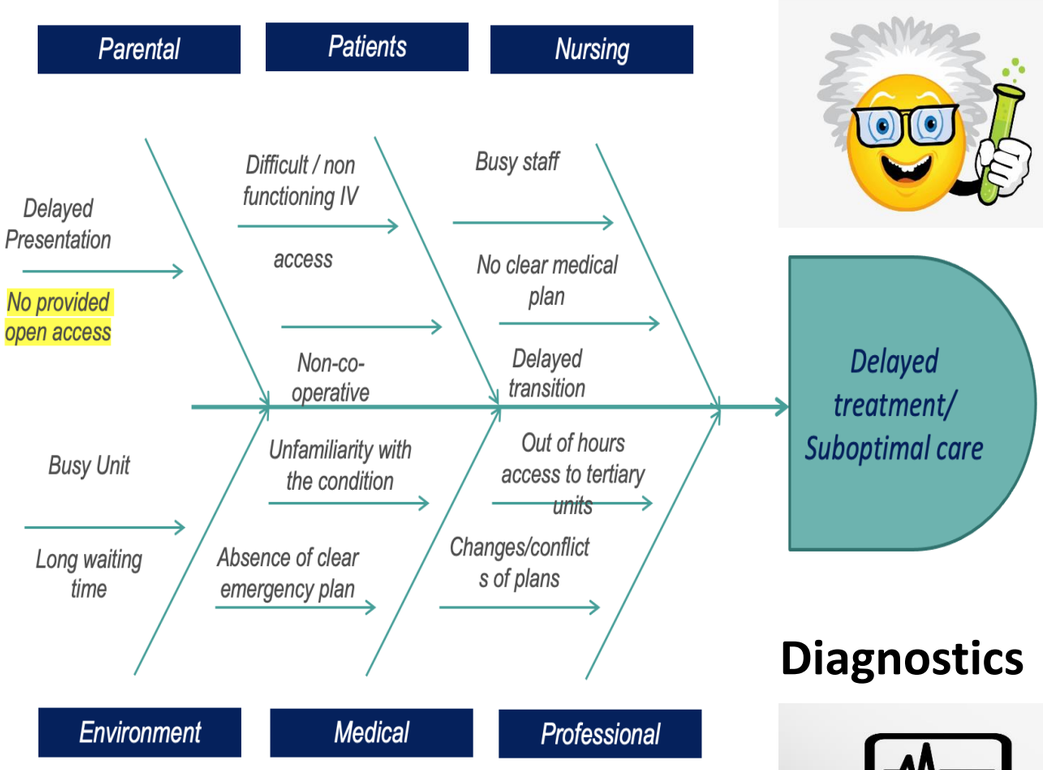
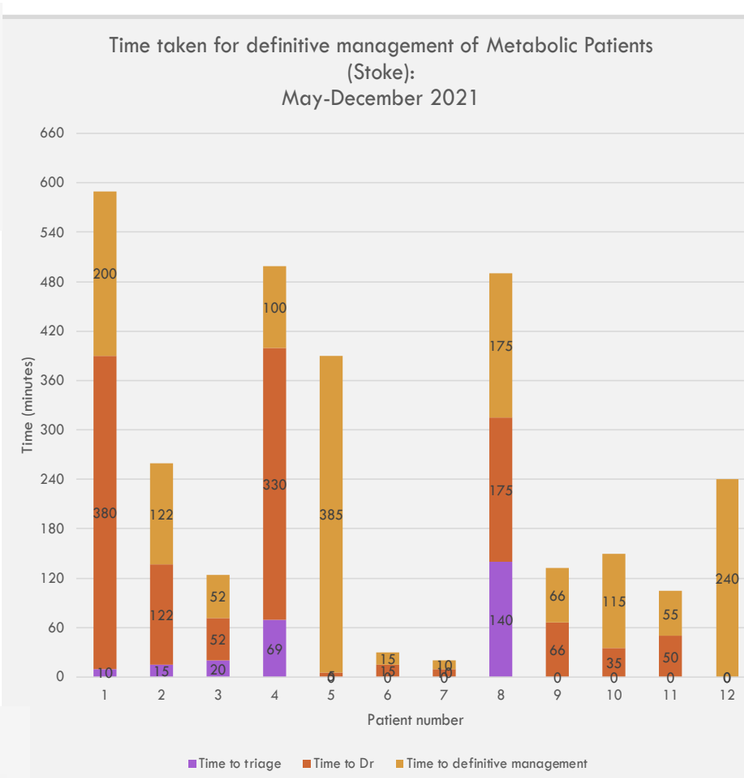


BACKGROUND

Data collected between may to December 2021 has shown that only 3 out of 14 acutely unwell Children with Inherited metabolic Disorders presented to our trust been seen and treated within 1 hour of presentation; this put them at risk of decompensation , long term organs damage, beside Prolonging hospital stay, and causing parental distress



Diagnostics



" we thought that fluids has been started in CAU hence why there was a delay in starting treatment"

" patient was sent home before blood results comes back, turned out that she needs admission for IV fluids"

"Fluids has been running overnight through Portacath before realising in the morning that the line was not working and fluids leaked under the skin "

Aim : by end of November 2023, the aim for children with Inborn error of Metabolism presenting acutely to the Hospital to be assessed and started IV fluid treatment (if required) within the hour

Measurements: time from their presentation to the children's assessment unit to the start of treatment

Inclusion criteria: children with IMD presenting acutely unwell to the hospital and requiring admission for IV fluid /Emergency regimen management

Exclusion criteria: children with IMD for elective admission/Blood tests/devices check, and children who already started Emergency regimen at home and not requiring IV fluid therapy

Sampling method: retrospective data collection from notes, on a 3 monthly cycles

Ideas of change

1- all registered patients with Inherited Metabolic disorders to have open access plan on the computer system stating that they should be seen and assessed within the hour if presented acutely unwell

2- Documentation of times of arrival, Triage, assessment, decision to treat, and time of treatment initiation

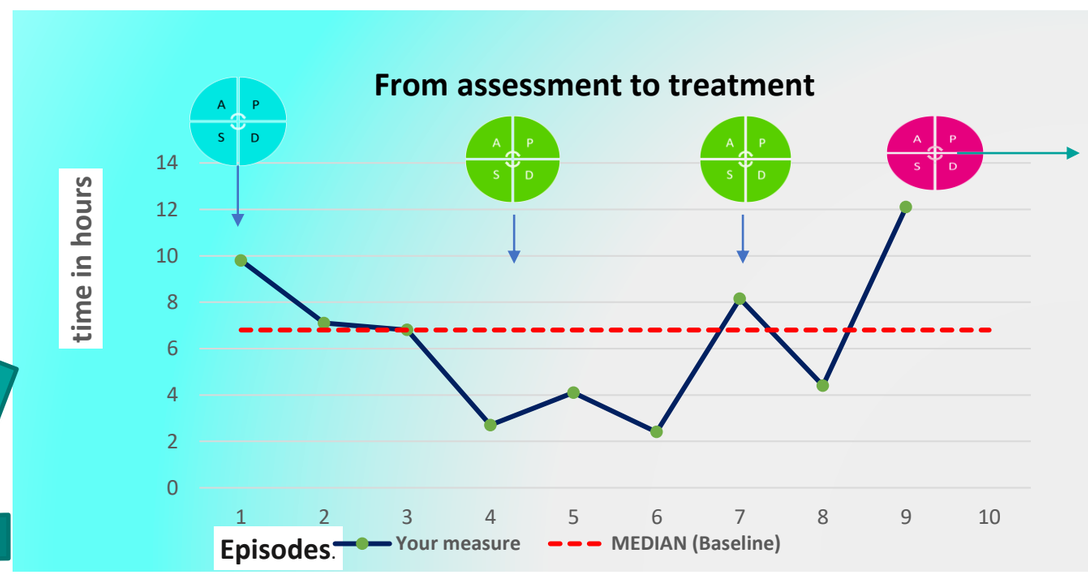
3- parents patient's passport and EMLA (numbing cream) to be provided in-case they need to come to hospital, and to engage them in care and management of their children

4- include a teaching sessions for doctors as part of their weekly departmental teaching sessions , and why not a Simulation or Problem based learning !

5- designing a Clerking sheet with a flow chart as a long term plan

PDSA

PDSA Test #	PLAN	Do	STUDY	ACT
1	To design flow chart for all patients with IMD with clear pathway, general guidance, references and contact numbers	Draft flow chart/pathway designed with help and support from my consultant	Difficult to execute as an initial step, needs a lot of work, revision, validation, cross-checking, referencing, and it is time consuming which will need more recruitment and effort	**Abandoned** It has been abandoned for the time being and to be reconsidered in the near future as a long term plan to be more structured and organised
2.1	To obtain list of all registered patients with Inherited metabolic disorders from main tertiary hospital (BCH) to check if they have an Open access plan on our data base and	- List of all patients Obtained(24) - Patients with no open access plans (6) were identified. - patients with open access plan stating that they should be seen within the hour (3) also identified	- Thorough discussion with the consultant paediatrician to complete and authorise the open access plans for patients who doesn't have any - update the existing open plans which will require liaising with tertiary hospital	**Adopted** and partially completed with ongoing efforts to complete and update all open access plans
2.2	To engage the junior doctors, registrars and consultants in this project to help implementing, sustaining and developing change	A 15 minutes QI presentation prepared and presented in the paediatric department audit meeting	Feedback for improvement included trying to engage parents in care by giving them hand held hard copies of their plans, and educating nurses about initial steps to be taken including informing doctors and performing baseline blood gas for certain patients	**Adopted/Adapted** Feedback considered valid To continue collecting data periodically to monitor progress
3	Think Parents: - Designing patient passport by liaising and collaborating with BCH inherited metabolic diseases team - Identify children who are distressed and afraid of needles and blood tests and provide EMLA/numbing cream in case they are unwell and presenting to the hospital for potential admission/blood tests - Identify children with difficult Intravenous access to minimise distress and trials of obtaining IV access, plus facilitating long term IV access if required	- Work toward Designing a new patient passport or liaise with BCH to adopt and obtain their patient's information sheet with the QR code to be distributed to patients who will be seen locally - Discuss with paediatric team the possibility of providing EMLA/numbing cream to parents with showing them how to use it efficiently - Discuss who might require a long term IV access provision to facilitate that	Awaiting discussions and feedback to determine further steps (TBC)	**Extend**



REFLECTIONS & LEARNING:

1- starting by improving small and simple things can be underestimated, but over time the impact is huge

2- I have learned that designing a flow chart is not as simple as it might look as it requires a huge effort, time and big team involvement

3- Data has showed that, Nurses are good at triaging the patients within reasonable time, but communication between team members is lagging which can result in delay

4- ongoing Data collection, implementation of small changes, and parents involvement in care and feedback needs to continue to ensure sustainable change

Acknowledgements:

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