Evaluation of multidisciplinary care of children with a variety of bone conditions at Royal Manchester Children's Hospital

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Introduction

Our multidisciplinary clinic was originally set up to see patients with osteogenesis imperfecta. We now see patients with a variety of bone disorders including hypophosphatasia, idiopathic juvenile osteoporosis and geroderma osteodysplastica. The aim is to assess if we as a paediatric metabolic bone disease team are meeting their needs.

Method

Over a 16-week period in 2021/2022, a paper questionnaire was given to patients or their parents/carers at the end of their clinic appointment. The questionnaire contained eight questions regarding the following:

- Satisfaction of attending a MDT clinic
- The usefulness of a written report following clinic
- The usefulness of reviews on the ward during infusions
- Helpfulness of school visits
- Helpfulness of home visits
- Services that they deemed useful to offer in the future.

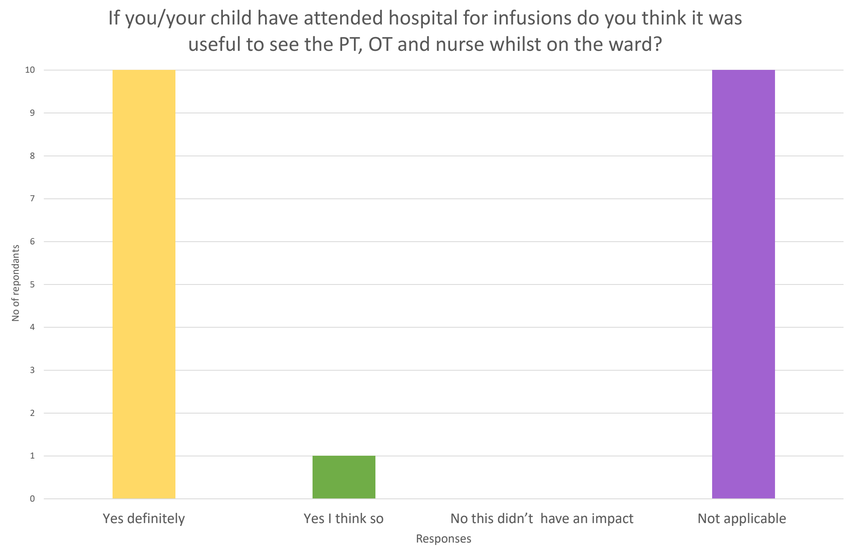
Results

- The questionnaire was distributed to 31 families with a response rate of 80.6%.
- Parents comprised 60% of the respondents and 40% were the patient (children from 11-16 years old).
- 100% of respondents rated their level of satisfaction with the multidisciplinary clinic as 8 or above, with 10 being the most satisfied.
- 100% rated the written report received following the clinic to be good or excellent.
- 44% of respondents were seen by Physiotherapists (PT), Occupational therapists (OT) and/or specialist nurse when in for infusion, 100% found it useful.
- Nursery/school/college visits had been carried out with 56% of patients and they all found this helpful.
- Home visits were carried out in 20% of respondents. They reported these as helpful.
- 60% of respondents contacted the nurse specialist for advice/support and all found it helpful.

Patients and families think it would be helpful to offer the following services in order of preference: hydrotherapy, family days, information sessions, transition clinic (joint), equipment advice (joint), information leaflets and wheelchair advice.

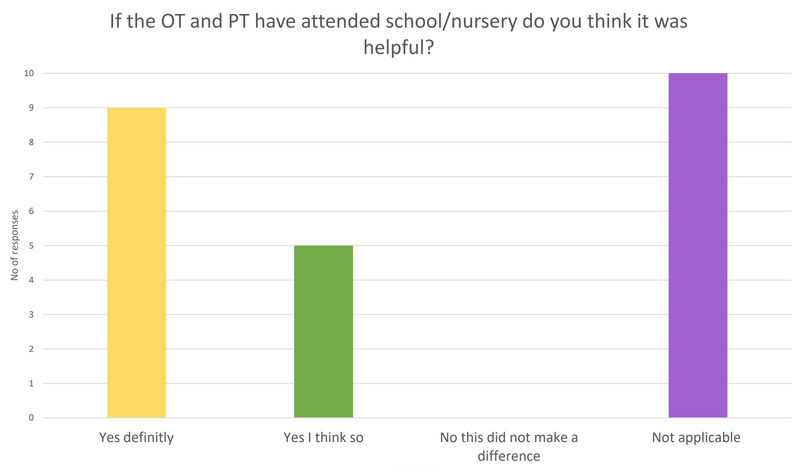
For the patients who required an infusion, 100% thought it was useful to see the PT, OT and nurse on the ward.

'Helpful to touch base if there are any issues that are relevant at the time.'
'It allows us to catch up and raise any concerns.'
'Any problem can be discussed and receive the relevant advice.'



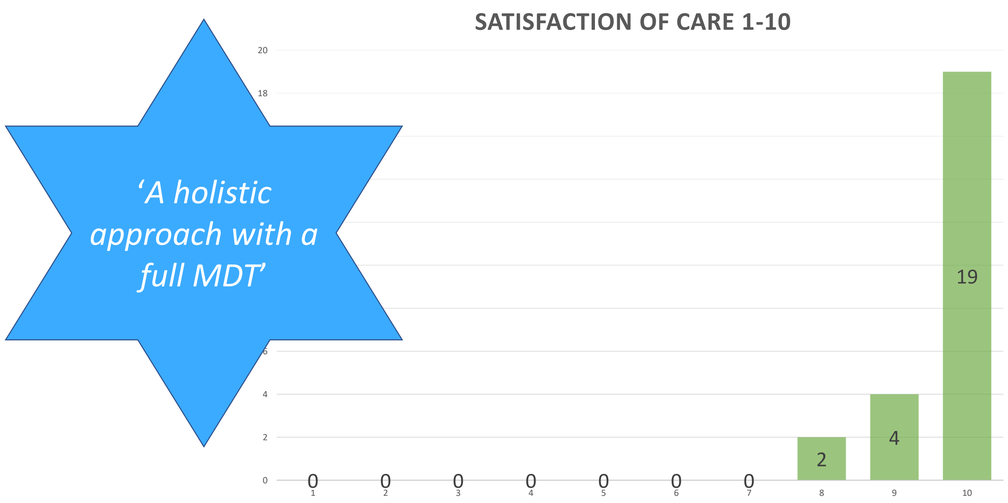
Patients and parents found it beneficial to have OT and PT attend their school.

'It made my school more aware of my needs.'
'It helped the school understand my child's needs and give them the confidence in their care, therapy etc. It helped that care plans are in place generally and for PE, adverse weather etc.'
'It helped formulate a meaningful EHCP.'
'They can see the child in a different setting and see what they need help with mobility.'



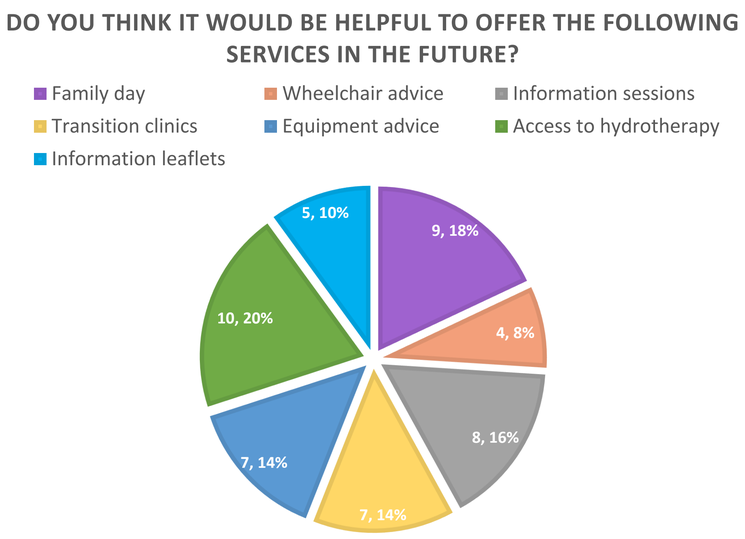
Themes

Patients reported that they felt listened to and involved in decisions/care.
'Siblings have the opportunity to be seen together to minimize appointments and coordinated around infusion appointments.'
'Seen on time, by all professionals to come up with a plan. This enables us to put forward any concerns to the team. Also, with everyone together means communication is better.'



Conclusion

Multiple opinions from patients/families of the metabolic bone service were positive. *'My child always looks forward to coming to MDT's because she knows she can be herself, she doesn't become worried and all the staff presenting are obviously child friendly.'* Suggesting we are meeting current needs. We are using this feedback to plan how to develop the service further.



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