

NP-3

How to support Hypoplastic Left Heart Syndrome (HLHS) Patients Management during Inter stage

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Introduction:

HLHS patients remain as an inpatient following their Norwood Stage I procedure until they have had the Glenn operation. This can mean an admission lasting up to 8 months in total with a long period between the Norwood Stage I and Glenn, referred to as inter stage.

This long stay may be an emotional burden for the families but also to staff caring for the patient during the admission.

The objectives of this project was to gain feedback from staff working on the ward about how they feel about looking after inter-stage HLHS patients.

Methods:

Quality improvement methodology (part of a trust leadership programme) was used to assess emotional impact on staff of caring for HLHS interphase patients. An emotional touch point model with a non-structured interview was used with two members of staff, and then a short feedback sheet was given to staff nurses, to gain a wider viewpoint on the issue and their thoughts and suggestions for how the situation could be improved

Results:

Many suggestions and thoughts were collated from both the emotional touch point exercise, and the feedback sheets. The common themes identified were:

Have a designated medical lead for HLHS patients on the ward during inter-stage

Daily routines/structured meetings

Teaching given to families to allow independence is positive

Teaching for SHO level at medical induction

Nurses felt they were included in planning by registrar/consultant level but dismissed by junior SHO level.

Nurse felt calm and capable, but at times frustrated when they can see a slight deterioration.

Conclusions:

Nurses primarily were confident caring for patients during inter stage management, but felt there were improvements to be made in relation to communication and structure.

Improving structure and supporting independence with the families, especially identifying a key medical lead, appeared a positive improvement that could be simply made to current procedures.

Also, we will implement an ANP ward round weekly for these families, with emphasis not just on medical stability but also development and weekly achievements.