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Future
Hospital

Nurse-led cardiac adolescent and transition service

This Future Hospital Programme case study comes from Great Ormond Street Hospital (GOSH). Here, Lindsay-Kay Leaver and Dr Sachin Khambadkone describe how their team established a new cardiac adolescent and transition service to help increase young people's understanding of the issues attributed with cardiac conditions.

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Key words: cardiology, patient-centred care, transition services, nursing, young people and adolescents, delivery of care, patient involvement

Person-centred care

Key recommendations

- Implement a service to provide inpatient and outpatient support to young people aged 12 and over and their families, to help manage the transition to adult services.
- Organise events, classes and workshops to help prepare young people for the transition of services as well as imparting information and knowledge regarding their conditions.

Local context

GOSH for Children NHS Foundation Trust is a dedicated paediatrics service that sees over 240,000 young patients visiting every year. Our referrals come from all over the country, as well as internationally. Our commitment to paediatric medicine helps us to find new and better treatments and cures for childhood illnesses. We are also world-renowned for the training of paediatric nurses and doctors.

The challenge

For a variety of reasons we found that young people were not getting transition support in cardiac services. These included:

- no dedicated nursing transition lead in cardiac services
- variable staff attitudes to transition importance
- low levels of transition training
- few written resources for young people
- no budget
- young people unwilling to travel to GOSH, in London
- administration system problems.

Our solution

In April 2012 I was appointed to the role of cardiac adolescent and transition clinical nurse specialist (ATCNS), following a recommendation in the Safe and Sustainable Review of Children's Congenital Cardiac Services in England. I was given a blank slate and encouraged by my managers and consultant cardiologist for adolescents, Dr Khambadkone, with whom I worked very closely, to develop the service in a way which would best benefit young people.

A nurse-led service was established to provide inpatient and outpatient support to young people aged 12 and over and families with structural congenital heart conditions, as well as to manage their transition to adult services. Currently, 1,050 young people are known to the service and 775 young people are seen in the transition clinic each year. Referrals are accepted from all multidisciplinary team (MDT) members, or young people and families can self-refer.

Staffing

Our team consists of myself as ATCNS, Dr Khambadkone, lead consultant cardiologist for transition, and an adolescent link nurse in each clinical area. Link nurses are offered study days and further training on transition and adult congenital heart disease and have the opportunity to shadow the ATCNS in clinic.

Methods

Young people were involved in service development and ideas were presented to the hospital's Young People's Forum (YPF) for feedback. We wrote and disseminated a transition policy and addressed problems with young people missing out on referral due to administration issues, highlighted through

Person-centred care

an audit. A transition individualised care pathway (ICP) was written and used. Later this was merged with that of Royal Brompton Hospital and Evelina London Children's Hospital to create a single ICP which could be used pan-London so that South East England provides standardised care.

We heavily publicised the transition service using posters and flyers throughout the hospital. I provide training to all new nurses within cardiorespiratory and all new registrars are given training to take part in transition clinic. To raise wider awareness a transition information board is displayed outside the main meeting room where departmental meetings are held throughout the week.

Young people in the service have a yellow sticker on the front of their notes to highlight their involvement with the transition service, which includes my contact details - staff can then easily identify teenagers and contact me for support. Link nurses in each clinical area were established to provide a named contact in each area for staff, young people and families. Link nurses are responsible for the transition information board and raising awareness in their respective clinical areas.

In collaboration with cardiac charities (British Heart Foundation and The Somerville Foundation) we produced written resources and short films for young people on generic cardiac transition, lifestyle and psychosocial issues which can be used by all sub-specialities within cardiology and nationally.

'After Rhythmic Beats parents and young people were less anxious and more knowledgeable about managing their condition.'

Lindsay-Key Leaver, Great Ormond Street Hospital

We established **tiered levels of care** so that each patient receives the most appropriate care for their needs.

Tier 1 - Young people receive an introductory information pack, my contact details, telephone and email support on request, an invitation to attend Rhythmic Beats and an invitation to attend a dedicated transition clinic run jointly with the adult service.

Tier 2 - In addition to the support offered in lower tiers, we design a transition individualised care pathway, and carry out a comprehensive transition assessment covering cardiac condition; lifestyle and health; advice on drugs, alcohol and smoking; exercise; diet; general health promotion; school and careers advice; promoting independence, and puberty and sexual health. Parents also receive advice and transition preparation. For example, if the young person lacks capacity, advice is given to families on managing healthcare, property and financial matters when they lose parental responsibility at 18. The UK government has published guidelines on making decisions for someone who lacks capacity.

Tier 3 - In addition to the support offered in lower tiers, involves support before, during and after cardiac catheter or cardiac surgery; in-depth, tailored support for young people and families with complex needs; advocacy and liaison with multidisciplinary team, and a joint appointment with me and the psychology team if required.

Young people attend transition clinic from age 12, meaning they are able to get to know the adult team while they are still in paediatrics. The transition clinic is held at GOSH and run by transition lead consultant Dr Khambadkone, the ATCNS and representatives from the adult team. Normally, young people transition to the adult service around age 16; however this is flexible and depends on the individual's needs and development.

Since February 2013 I have been running a transition event at GOSH called Rhythmic Beats, an intensive 1-day group transition event which provides information on topics discussed in tier 2 level care. Rhythmic Beats consists of talks and workshops where we can provide information, answer queries and signpost to sources of support to large numbers of young people and families. We collaborate with a

Person-centred care

number of cardiac and adolescent charities who volunteer their time and resources. A lunchtime 'marketplace' is held where young people and families can meet one another and visit stalls run by the charities to gather further advice or support.

I have established links with the other two London Congenital Heart Surgical Centres (Royal Brompton Hospital and Evelina London Children's Hospital) and invited young people and staff from these centres to also attend Rhythmic Beats. This pan-London Rhythmic Beats event enabled large numbers of young people to benefit from the format and has proved successful.

'It is a great privilege being part of the Members' Council and the YPF as it is important that patients' voices, and in particular young peoples' voices, are heard within the hospital.'

Head of the Young People's Forum, 23 November 2013

Key learning

Staff engagement with transition began to change once they saw the ways in which my service could help support patients and relieve their workload, for example, in addressing 'difficult' subjects like contraception, puberty, teenage pregnancy, drug use and mental health problems.

Referrals to the transition service increased and from a younger age. MDT members have also requested support from the ATCNS with patients and writing adolescent policies. Teaching sessions were requested, now transition teaching is a standard session for all new ward and cardiac intensive care staff.

Audits were a useful tool for highlighting which young people were not getting transition support and the reasons for this. For example, some were never referred by their paediatric cardiologist, some were referred at a late age leaving little time to offer transition support, whilst others were referred but admin systems meant the referrals were not processed correctly. Once we knew the reasons behind absent referrals we were able to address these through education and awareness of the importance of transition and the role of the transition service and meetings with admin staff to implement system improvements.

There were variable staff attitudes to the importance of transition and low levels of staff training on transition. We heavily publicised the transition service using posters and flyers throughout the hospital. I provide training to all new nurses within cardiorespiratory and all new registrars are given training to take part in transition clinic. To raise wider awareness, a transition information board is displayed outside the main meeting room where departmental meetings are held throughout the week. Link nurses were established in each clinical area to disseminate transition information, raise awareness and champion improvements for young people in their respective clinical areas. A transition update email is disseminated annually to all staff within cardiorespiratory. Transition study days and conferences are advertised and staff supported to attend.

We have really struggled to get young people to engage with one another. We promote social activities and groups run by cardiac charities; these are fully funded, however the majority of young people don't want to attend these. The way we have succeeded is to set up situations where social interaction is a by-product rather than the main focus so interactions and friendships establish in a more natural way. As such, the group talks, workshops and communal lunch during Rhythmic Beats give young people and their parents the opportunity to engage with one another through a shared experience rather than in a forced artificial way. We have also had success in running research with young people and they have formed fantastic friendships by participating in our research group. Again, the social interaction is a by-product of another activity but we engineer it to be that way.

Person-centred care

Resources

When I started the service in 2012 there were very few resources available for young people. In collaboration with cardiac charities (British Heart Foundation and The Somerville Foundation) we produced written resources and short films for young people on generic cardiac transition, lifestyle and psychosocial issues which can be used by all sub-specialities within cardiology and nationally.

The ATCNS service has no allocated annual budget. Unfortunately, it has not been possible to fund additional new roles within the ATCNS service. The BHF Alliance scheme for cardiac professionals assists with education costs. Establishing close working relationships with charities has been invaluable; their support and generosity has played a huge part in the success of the service.

GOSH cardiologists cover a large geographical area within their outreach clinic network. Some young people are unwilling to travel to GOSH, in London to attend transition clinic. These young people are offered tier 1 level care and are prioritised to attend Rhythmic Beats as they will often prefer to attend an all-day transition event once over multiple visits to transition clinic. If young people decline a referral to the transition clinic they are offered tier 2 or 3 level care should they attend GOSH for cardiac investigations, surgery or procedures. Young people and families are able to contact the ATCNS for support via email or telephone.

*'This is a brilliant opportunity and I feel honoured that you are asking me!
This is something that I would love to take part in.'*

Head of the YPF, 13 November 2013

Education

Rhythmic Beats was very challenging to set up as it involved a vast amount of planning, coordination and time and there was no budget available to fund the events. Considerable time was spent sourcing and establishing relationships with the various organisations and charities, and planning the talks and workshops. External charity donations fund the catering and venue hire. I had no administrative support for the first 2 years so I had to send all the appointment letters myself for 11 Rhythmic Beats events.

Feedback was gathered after each event and after a year of running Rhythmic Beats monthly I reviewed the event and feedback was gathered from young people, parents, staff and the charities and organisations involved. Based on the feedback I proposed running a larger Rhythmic Beats less frequently and made some alterations to the content and format of the talks and workshops. I presented the findings and suggested developments to GOSH's Young People's Forum for their consideration. The Young People's Forum agreed with my proposals and in 2014 a revamped Rhythmic Beats was launched. Administrative support has been in place since 2014 and this has been enormously beneficial for the ATCNS service. Outcome measures are gathered at each Rhythmic Beats to measure young people's and parents' satisfaction and knowledge levels around the issues discussed.

Outcomes

Outcome measures from Rhythmic Beats:

Young people rated the day as 7/10. Parents rated the day 8/10. In total the day was 7.5/10.

- 84% of young people were more confident about managing their condition
- 95% of young people knew of charities and support available to them
- 70% of parents said the day improved their confidence 'a lot'.

When asked what was the least useful part of the day, 71% of parents and 61% of young people left the question unanswered which we took as an indicator that they had found all parts of the day useful.

Person-centred care

When asked what was the most useful part of the day, 40% of parents and 38% of young people thought it was meeting others and sharing experiences.

13% of parents had no worries about transition prior to attending Rhythmic Beats and 40% had no worries after attending.

Before Rhythmic Beats, 31% of parents were worried about the level of care their child would receive in the adult hospital and only 1% of parents were worried about this after Rhythmic Beats.

46% of young people had no worries about transition prior to attending Rhythmic Beats and 71% had no worries after attending.

When asked what would help them to transition well, 24% of young people thought it would be helpful to meet the adult team prior to transitioning and 28% wanted to learn about the transition process – both of these are covered during Rhythmic Beats.

Young people and parents rated their knowledge level of various topics before and after Rhythmic Beats. Knowledge improved significantly in the majority of topics however decreased slightly for lifestyle topics. We felt this was because young people and parents initially overestimated their level of understanding of lifestyle topics and how they affect congenital heart disease.

Next steps

I am currently undertaking a national evaluation of congenital heart transition services. This will establish the current level of service provision nationally, serve as a baseline against which to measure change and will lay the ground work for future transition studies. In addition, we are hoping to expand the ATCNS team and develop a congenital heart disease transition website.

Information about resources and how to order them can be found at [the British Heart Foundation's YHart page](#).

This case study is not an endorsement of any individual or organisation. The material within is promotional only and we do not necessarily reflect the views of the author and the organisation they represent.

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