

G20

PARENTS EXPERIENCES OF GOING HOME WITH THEIR INFANT FOLLOWING FIRST STAGE CARDIAC SURGERY FOR SINGLE VENTRICLE HEART CONDITION

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Aims The study presented here retrospectively explored how parents felt about going home with their infants following first stage cardiac surgery for single ventricle heart.

Methods Parents, all members of Little Hearts Matter (LHM, a UK Congenital Heart Disease Charity) completed an online questionnaire which asked about family demographics, time of diagnosis, location of specialist heart centre, distance from home, discharge information, social support, confidence, anxiety and how parents felt at the time of discharge (T0) and at the time of completing the questionnaire (T1). A non-experimental survey design was used; the questionnaire was structured so that both parents could answer the questions independently. 62 families with infants aged between 0–2 years were sent an email via LHM inviting them to complete the online questionnaire during Nov 2012. There were 22 responses (35% response rate) from 6 couples, 15 mothers and 1 father. Care had been received at 11 different specialist cardiac centres across the UK and 1 in Australia.

Results The answers from the open ended questions which explored how parents felt about going home and their experiences were thematically analysed using an inductive approach. Five main themes arose: Mixed emotions ‘fear versus excitement’; the need for effective discharge preparation for parents; the need for effective discharge planning and preparation for community staff and local hospital teams; the need for access to information and advice (once home) and gaining control: the need to return to family functioning.

Conclusion The study confirms anecdotal experiential evidence and has provided new insights into factors that may be associated with discharge from hospital to home for parents of infants with complex congenital heart disease. Implications for the review of children’s congenital cardiac services will be discussed specifically in relation to the discharge support role of ward nurses, children’s cardiac nurse specialists, psychologists and community teams.

G21(P)

ACUTE PAIN TREATMENT IN A PAEDIATRIC HOSPITAL SETTING: WORKING TOWARDS UNDERSTANDING EDUCATION NEEDS AND AN ALGORITHM FOR REFERRAL TO THE SPECIALIST PAIN SERVICES

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Aims Pain management has become more complex. Referral to specialist pain teams is commonplace in many children’s services. This paper reports on a review undertaken with 2 aims: 1) assess how patients’ pain was managed before, after and without specialist intervention, to identify non-specialised staff education needs regarding routine and non-routine pain management; 2) develop supporting evidence to inform an algorithm

promoting appropriate referral of children needing more complex pain management to the pain service.

Methods Prospective notes and treatment chart review and real time logging of referrals of all patients referred prospectively to an acute paediatric pain service during a two week period in September 2013. Comparison data were extracted from patients not referred but likely to have similar pain management needs during the timeframe. =Patient history, drug therapy and pain scores were extracted. Following the review, semi-structured interviews were conducted with a range of clinical staff responsible for managing children’s pain to explore their perspectives and local contextual factors aiding or preventing optimal pain management.

Results Fifteen patients were referred to the service. The majority were post-surgery and prescribed patient or nurse controlled analgesia or epidural infusion. Such referrals tended to be to address unresolved pain. In general, of the 15 cases and 15 comparisons, referrals /non referral were appropriate and there was little indication of over-reliance on the pain team or inappropriate access. Detail from the cases will be examined with respect to the insight they provide to pain management, service delivery and staff awareness.

From the interviews it was clear that despite this finding, reflecting an unusually quiet period, there are structural and organisational issues which can cause lack of clarity about the role and remit of the team.

Conclusion The data reveal a problem found where services have evolved from a need which has changed over time with the team in a static state. Since review, the service has developed, reflecting the uncertainties and concerns of staff interviewed. Reflection on the purpose and provision, and observation of, a specialised service can help ensure it remains fit for purpose and specific concerns allowed to surface.

G22

SUPPORTING AND SHARING: YOUNG PEOPLE’S ENGAGEMENT IN AN ONLINE SUPPORT FORUM IN THE CONTEXT OF LIVING WITH CYSTIC FIBROSIS

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Aims Young people with long-term conditions learning how to care for their condition can benefit from social support from their peers. However, for young people with cystic fibrosis (CF) the opportunity to do this is limited due to segregation policies written to prevent cross-infection. Therefore, online support groups could play a significant role but this is an under-researched area. This paper explores how young people with CF used a condition specific online discussion group to support self-care.

Method An online ethnographical approach was used to explore the social interaction of 97 young people with CF, posting to a Charity website over a period of four months. Virtual non-participation observation of 48 discussion threads was conducted. Analysis was conducted using a Grounded Theory approach. Both authors conducted the analysis.

Findings Young people posted queries and engaged in discussion regarding the management of pharmacological and non-pharmacological therapies but in the main discussed concerns and strategies for living with CF. Young people found the group to be a