

Methods Two cohorts of SCD children and age and ethnic matched controls were recruited. Cohort one (47 SCD children and 26 controls) had a median age of 8.8 years at recruitment and were followed for two years. Cohort two (45 SCD children and 26 controls) were recruited at an older age (median age 10.2 years) than cohort one ($p = 0.007$) and were followed for ten years. Forced expiratory volume in one second (FEV_1), vital capacity (VC), forced expiratory flow between twenty-five and seventy-five% of VC (FEF_{25-75}), total lung capacity (TLC) and residual volume (RV) were measured at recruitment and at the end of follow-up.

Results In both groups of SCD children, but in neither control group, lung function declined significantly. The rate of decline was greater in cohort one than cohort two for FEV_1 ($p = 0.008$), VC ($p = 0.001$), FEF_{25-75} ($p = 0.030$), TLC ($p = 0.004$), and RV ($p = 0.043$). During follow-up, ACS episodes were more common in cohort one than cohort two (one episode per 1.93 patient/years versus one episode per 12.6 patient/years) $p < 0.0001$. ACS episodes were the only independent predictor of a greater decline in lung volumes.

Conclusions Lung function deteriorated in SCD children compared to similar aged and ethnic matched controls. The most rapid period of deterioration took place during early childhood when ACS episodes were more common. Our results suggest that treatment strategies to prevent ACS episodes need to be started in young SCD children if they are to be most effective in preventing the decline in lung function.

G402

THE IMPACT OF A STANDARDISED TRANSCRANIAL DOPPLER TRAINING PROGRAMME IN SCREENING CHILDREN WITH SICKLE CELL DISEASE: A EUROPEAN MULTI-CENTRE PERSPECTIVE

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Background Routine use of Transcranial Doppler (TCD) screening is standard management for the prevention of Stroke in children with Sickle Cell Disease (SCD). However, due to a number of factors including the lack of adequately trained TCD operators, less than 50% of children receive this service. The study objectives were to determine the effectiveness of modular TCD training, to improve the quality and standardisation of TCD assessment and thereby facilitate an increase in the number of children screened.

Methods The modular training programme comprised of a two-day course, covering theory and practical aspects of TCD and incorporating significant hands-on instruction. This was followed by local scanning with continuous monitoring and feedback from the training centre in the United Kingdom (UK). Competency evaluations were undertaken at the end of the instructional course and 6–12 months later when a log book of at least 50 scans was completed. Data were compared with that acquired from the same patients in the year prior to the training programme using imaging and/or non-imaging TCD. Statistical

analysis was performed using Pearson Chi-Square controlling for possible treatment bias.

Results Data were obtained from 326 patients (male 168 (51.5%); female 158 (48.5%); mean age 7.6 ± 3.5 , range 1–17) in the UK, Ireland and Italy. Genotypes were; HbSS 79%, HbSC 19%, HbSbetathalassaemia^o 1%, HbSbetathalassaemia⁺ 1%. 462 pre-training scans (imaging and/or non-imaging TCD); 134 from the UK, 193 from Ireland and 135 from Italy, and 377 post-training scans were available; 114 from the UK, 167 from Ireland and 43 from Italy. Statistical analysis revealed a significant difference in the STOP distribution between the three centres ($C^2 = 53$, $p < 0.001$) prior to training, with no treatment bias (no treatment $C^2 = 47$, $p < 0.001$; treatment $n = 82$, $C^2 = 23$, $p < 0.001$). Anomalous technique between centres pre-training included the erroneous use of Doppler angle correction, poor vessel/Doppler angle optimisation and inconsistent STOP velocity thresholds for imaging and non-imaging studies. After training the STOP distribution was similar in the three centres ($C^2 = 7.1$, $p = 0.311$; no treatment $C^2 = 11$, $p = 0.074$; treatment $n = 81$, $C^2 = 7.8$, $p = 0.252$). The consistent STOP distribution post-training, achieved using either imaging or non-imaging TCD,

Conclusion This is the first modular TCD training programme that has demonstrated efficacy when delivered in different European countries. TCD was either imaging or non-imaging techniques and should facilitate the more widespread.

G403

ASSESSING THE VALUE OF BONE MARROW ASPIRATE AND TREPHINE IN IDENTIFYING METASTATIC INVOLVEMENT IN CHILDREN WITH EWING'S SARCOMA: A RETROSPECTIVE SINGLE CENTRE EXPERIENCE

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Background Bilateral Bone marrow aspirates and trephines are part of the initial staging evaluation of patients with Ewing's sarcoma. However, the utility of performing this invasive investigation in addition to imaging with MRI and Technetium 99 bone scan has not been assessed.

Aim To assess the value of performing bone marrow aspirates and trephines in identifying metastases when compared to imaging, particularly Technetium 99 bone scan.

Methods Retrospective review of 48 children aged 16 and under with Ewing's sarcoma treated in our institution over a 14 year period (August 2000–September 2014).

Results The demographic details of our patients were as follows—we treated 25 males and 23 females (M:F = 1.08:1). 54% of patients were over 10 years old while 12.5% of patients were under 5 years old; the remaining 33.3% were aged between 5 and 10 years. Using imaging alone, 69% had localised disease while 31% had metastatic disease. 81% of patients ($n = 39$) had bone marrow aspirates and trephines performed, of which 3 were positive for disease; one of these patients had a pelvic primary and the marrow was positive on the left side which was the location of the primary site. 43 patients (90%) had a bone scan, of which 10 were positive for bony metastases. All three patients who had bone marrow positivity also had metastatic

lesions on bone scan. 4 patients with metastatic bony lesions did not have a bone marrow performed, while the other 3 did not have evidence of disease in the bone marrow aspirate or trephine.

Conclusions Although our numbers are small, there is a high correlation between bony metastases identified by Technetium 99 bone scan and bone marrow aspirate and trephine positivity. Further prospective evaluation is required to determine whether a bone marrow examination adds any value to the initial staging of Ewings sarcoma over currently available imaging techniques and whether it can be omitted from the list of initial staging assessments.

G404 MODELS OF KEY WORKING IN CHILDREN'S CANCER CARE: PROFESSIONALS AND PARENTS VIEWS

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Purpose The importance of the key worker role in promoting continuity and coordination of care for children with cancer and their families is recognised but evaluation of such services is less well developed with little information available about different patterns of provision and the determinants for success. Therefore, our aims were: identify models of key working and influencing factors; analysis of professionals and parents' views of the impact of the key worker role on families' experiences.

Methods Thirty-six semi-structured individual interviews and one focus group (n = 12) with key workers and twenty-eight interviews with parents were conducted. Multiple case study method was used to identify the models of key working developed and the impact on families' experiences.

Results Four models of care were identified. These models are organised along two dimensions - presence/absence of home visits and presence/absence of direct delivery of clinical care. Key worker involvement in care coordination and home visits was influenced by the resources available, in the hospital and in the community, these included staff and caseload numbers. Parents viewed the key worker role as a reliable, consistent, approachable source of support. The support was tailored to parent's needs and included information and advice, emotional and practical support. Having a main point of contact was highly valued by parents. In particular, parents identified the proactive and responsive nature of the service as central to the value they placed on it. However, some parents recognised the pressures on the key worker to support all the families in their caseload. Consequently, some parents described rationing their demands on the service in the context of other people with greater needs or feeling sometimes that the key worker was not available.

Conclusion The key worker role is instrumental in enabling families and patients to access and navigate services. The complexity of families' needs throughout the cancer journey is reflected in the complexity of the key worker role. Regardless of the model of care developed, core characteristics of the role and its impact on families' experiences were identified, these include: coordination of care, being a main point of contact and information.

G405 DEFINING HEALTHCARE PROFESSIONAL COMPETENCE FOR WORKING WITH TEENAGERS AND YOUNG ADULTS WITH CANCER – A BRIGHTLIGHT STUDY

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Aims Teenage and young adult (TYA) medicine is emerging as a distinct speciality, acknowledging the core tasks required to enable a young person to transition successfully to adulthood. As healthcare education is subdivided into adult or child focused-training, a framework is needed to reflect the specific competencies required to care for this population. The aim was to provide international consensus on the competencies required by healthcare professionals to provide specialist cancer care for TYA.

Methods A modified, international e-Delphi survey was conducted over 2 rounds. Experts were defined as professionals having worked in TYA cancer care for more than 12 months. They were identified through publications and invitations via professional organisations. The content of round 1 was informed by UK pilot work and a workshop undertaken by the professional organisation, TYAC. There were 87 closed-ended questions with responses on a 9-point Likert scale and further open-ended responses to identify other skills, knowledge and attitudes. Round 2 contained only items with no consensus in round 1 and suggestions of additional items of competency. Consensus was defined as a median score ranging from 7–9.

Results A total of 179 registered to be members of the expert panel, of which valid responses were available for 158 (88%) in round 1 and 136 (86%) for round 2. The majority of participants were nurses (35%) or doctors (39%) from Europe (55%) or North America (35%). All 87 items in round 1 reached consensus with an additional 15 items identified for round 2. The most important skill was reported as “being able to identify the impact of disease on young people's life”; the most important area of knowledge was “know about side-effects of treatment and how this might be different to those experienced by children or older adults”; “ability to talk about difficult issues” was the most important communication skill and honesty the highest rated attitude.

Conclusions The process has been successful in identifying a high degree of consensus for competencies and skills to be used of training for professionals working with TYA.

G406 COPING WITH CANCER – SUPPORTING YOUNG PEOPLE'S RESILIENCE

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Aims

- To better understand the help-seeking behaviour and information needs of young people with cancer, and how quality support and information can help them build and maintain