

frequency of malignancies in BS represents that in the general population, this is the first report of a paediatric patient developing AML following treatment for ALL. This girl was found to carry two novel *BLM* mutations, *c.1221-1G > A* and *c.1624delG*. This case documents the short interval at which treatment-related myeloid malignancy may occur in a child with BS and implies a fundamental role for *BLM* for normal haematopoiesis, in particular in the presence of genotoxic stress. It demonstrates the importance of molecular analysis in atypical cases of childhood malignancies. Novel approaches are required to improve treatment for these individuals as optimal dose delivery to often aggressive malignancies is hindered by extreme sensitivity to treatment toxicity.

**G175 THE IMPACT OF SOCIAL ISSUES ON THE HEALTH OF CHILDREN PRESENTING TO TWO TERTIARY PAEDIATRIC SICKLE CELL CENTRES**

doi:10.1136/archdischild-2013-304107.187

<sup>1</sup>A Swordy, <sup>2</sup>G Hann, <sup>3</sup>A Robins, <sup>2</sup>O Wilkey. <sup>1</sup>Institute of Child Health, University College London, London, UK; <sup>2</sup>Department of Paediatrics, North Middlesex University Hospital, London, UK; <sup>3</sup>Department of Paediatrics, Whittington Hospital, London, UK

**Background** Sickle cell disease (SCD) is an inherited blood disorder which affects 1 in every 2000 children born in the UK. Specialist clinics for children with SCD have identified that attending children live in areas of high deprivation, with many experiencing child protection issues.

**Aims** This study aims to examine the burden of social issues on this population of children with SCD, and investigate the impact of these factors on adherence to medication, clinic attendance, and inpatient admissions.

**Method** A retrospective notes audit of 360 children from two tertiary sickle cell referral centres was carried out and information on patient and family characteristics, social background and child protection issues, compliance with penicillin and immunisations was collated in line with national guidelines.

**Results** Housing problems were present in 25.8% of patients, immigration in 10% and child protection issues in 9.2%. 22.7% of patients were from single-parent families. The hospitals had good records for immunisations, (93.3% up-to-date), but poor clinic attendance, (mean attendance rate 71.87%). Attendance was higher with a more severe phenotype but not significantly different with social issues. Poor compliance was identified in 15% of patients. Strong associations exist between poor compliance and poor clinic attendance, not being fully immunised and the presence of parental SCD. There was a significantly higher incidence of inpatient admissions in patients with housing issues as compared to those without at both hospitals (Unit 1:  $p \leq 0.017$ ; Unit 2  $p \leq 0.027$ ; combined in multivariate model  $p \leq 0.04$ ). There was also a higher incidence of inpatient admissions in patients with immigration issues than those without, however this was not statistically significant ( $p \leq 0.28$ ). There was no difference in inpatient admissions between single-parent and two-parent households.

**Conclusion** The significant burden of social problems and child protection issues in the paediatric sickle cell population studied must be recognised due to the impact on patients' health, admissions to hospital, ability to attend clinic, and maintain compliance. Further research on causation of poor clinic attendance and poor compliance would reduce waste and improve health service efficiency, as well as being of considerable benefit to patient health and wellbeing.

**G176 THE NATIONAL CANCER SURVIVORSHIP INITIATIVE: A NATIONAL APPROACH TO IMPROVE THE QUALITY OF AFTERCARE FOR SURVIVORS OF CHILDHOOD CANCER**

doi:10.1136/archdischild-2013-304107.188

<sup>1</sup>H Jenkinson, <sup>2</sup>F Gibson, <sup>3</sup>P Morris, <sup>4</sup>M Stevens, <sup>5</sup>H Hatcher, <sup>6</sup>A Glaser, <sup>7</sup>A Toogood, <sup>2</sup>G Levitt. <sup>1</sup>Department of Paediatric Oncology, Birmingham Children's Hospital NHS Foundation Trust, Birmingham, UK; <sup>2</sup>Department of Paediatric Oncology, Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK; <sup>3</sup>NHS Improvement – Cancer, Institute of Health Service Management, London, UK; <sup>4</sup>Department of Paediatric Oncology, Bristol Royal Hospital for Children, Bristol, UK; <sup>5</sup>Department of Oncology, Addenbrooke's Hospital, Cambridge, UK; <sup>6</sup>Department of Paediatric Oncology, Leeds Teaching Hospitals NHS Trust, Leeds, UK; <sup>7</sup>Department of Endocrinology, University Hospitals Birmingham NHS Foundation Trust, Birmingham, UK; <sup>8</sup>London South Bank University, London, UK; <sup>9</sup>University of Bristol, Bristol, UK

**Aims** The National Cancer Survivorship Initiative [NCSI] (a partnership between the Department of Health, NHS Improvement, third sector organisations and user representatives) was established to improve the care provided for patients 'living with and beyond cancer'. It sought to work with cancer survivors to inform new models of care. The focus was to shift from traditional hospital-based models of aftercare to informed personalised patient care. The NCSI children and young people's [CYP] work stream sought specifically to design functional, cost-effective models of care underpinned by evidence.

**Methods** A multi-professional, multi-staged approach was used. Following an initial period of consultation, centres around England were invited to submit a service improvement project. Ten sites providing cancer care for children and young people were selected. Each site tested potential areas of change across newly-defined patient pathways, each led by an experienced clinician with service improvement input as well as significant input from young people and parents. The aim was to gather baseline evidence, test concepts and disseminate reports nationally to share learning more widely. Four centres were invited to test the models of care.

**Results** Evidence emerged in support of: clinical risk stratification to allow patients to receive care tailored to their individual need, personalised patient information in the form of a treatment summary and care plan, holistic needs assessment, alternative models of care to replace traditional consultant-led follow up including nurse-led care, telephone support and supported self management, psychosocial screening. Emerging from this work three different CYP patient pathways have been developed which are felt to represent gold standard care for survivors of childhood cancer at different stages of follow up and of differing risk groups.

**Conclusions** Comprehensive stakeholder collaboration, robust service improvement strategies and sharing of good practise and learning, have resulted in the development of evidence-based and sustainable packages of care for the growing cohort of survivors of childhood and young adult cancer. Spread and implementation are underway, using face-to-face and web-based interactive formats, to influence service delivery that can be adapted to suit local circumstances and resources.

**G177 A SINGLE-CENTRE EXPERIENCE OF CENTRAL VENOUS LINES IN PAEDIATRIC HAEMATOLOGY/ONCOLOGY PATIENTS OVER FIVE YEARS**

doi:10.1136/archdischild-2013-304107.189

<sup>1</sup>RYM Toh, <sup>1</sup>H Mackay, <sup>2</sup>A Isaac, <sup>3</sup>C Keys, <sup>2</sup>AB Edgar, <sup>1,2</sup>WH Wallace. <sup>1</sup>College of Medicine and Veterinary Medicine, University of Edinburgh, Edinburgh, UK; <sup>2</sup>Department of Paediatric Haematology and Oncology, Royal Hospital for Sick Children, Edinburgh, UK; <sup>3</sup>Department of Surgical Paediatrics, Royal Hospital for Sick Children, Edinburgh, UK

**Background and Aims** Safe central venous access is required for the management of paediatric patients with solid and haematological malignancies. The objective of this study was to retrospectively review central venous lines (CVL) experience in a single centre over a five-year period between 2007 and 2012 to determine the prevalence of line-associated complications and predisposing factors for premature line removal.

**Methods** All patients had either a single or double lumen external catheter (Hickman) or Portacath inserted. The choice of catheter for each patient is individualised. The Lothian Surgical Audit System, TRAK, iLAB and case notes were reviewed for patient demographics, surgical details of line insertion, line-associated complications and reasons for removal of line.

**Results** 140 patients underwent 213 line insertions, with 80 (57.1%) patients experiencing a line-associated complication (total number of episodes  $n = 145$ ). Proven infection was the most common complication (77 episodes, 53.1%), followed by blockages (43 episodes, 29.7%), dislodgement (12 episodes, 8.3%), fracture (7 episodes, 4.8%), kinking (2 episodes, 1.4%), migration (1 episode, 0.7%), extravasation (1 episode, 0.7%), atelectasis (1 episode, 0.7%) and skin breakdown over Portacath (1 episode, 0.7%). The median (range) number of catheter days for single CVL was 309.5 days (range 9–1357 days) for Portacaths and 82.5 (15–218 days) for Hickman lines. The median catheter duration for double CVL was 198.5 (1–582) days and 112 (0–882) days for Portacaths and Hickman lines respectively. Single Hickman lines had the highest rate of premature removal (42.9%), followed by double Hickman lines (42.6%), double Portacaths (35.7%) and single Portacaths (22.9%). The presence of severe thrombocytopenia ( $<50 \times 10^9/L$ ) and severe neutropenia ( $<0.5 \times 10^9/L$ ) at insertion were associated with higher rates of premature removal due to infection (20.0% and 19.6% respectively), compared with CVL with platelet count  $\geq 50 \times 10^9/L$  and neutrophils  $\geq 1.0 \times 10^9/L$  (18.3% and 18.2% respectively).

**Conclusion** Single Portacaths are the longest surviving central venous lines. The presence of thrombocytopenia and/or neutropenia at the time of insertion may be associated with an increased risk of line sepsis and premature removal.

## G178 WHAT DO GPs AND BEREAVED PARENTS THINK ABOUT PAEDIATRIC ONCOLOGISTS AND PALLIATIVE CARE?

doi:10.1136/archdischild-2013-304107.190

<sup>1</sup>SJ Neilson, <sup>1</sup>C Clifford, <sup>1</sup>F Gibson, <sup>1</sup>SM Greenfield. <sup>1</sup>School of Health and Population Studies, University of Birmingham, Birmingham, UK; <sup>2</sup>Paediatric Oncology Outreach Team, Birmingham Children's Hospital NHS Foundation Trust, Birmingham, UK; <sup>3</sup>Department of Children's Nursing, London South Bank University, London, UK

**Aim** The aim of the study was to examine the experiences of bereaved parents and general practitioners (GPs) following the death of a child with cancer within the family home. This presentation focuses on one of the findings; the parent and GP views on the hospital consultants' involvement in the palliative care.

**Design** A community based qualitative study.

**Setting** West Midlands region, UK.

**Participants** Purposeful sample of 18 GPs and 11 bereaved families. The sample was drawn from the families and GPs of children who had been treated for cancer at a regional childhood cancer centre and who subsequently died within the family home.

**Methods** One-to-one semi-structured tape-recorded interviews were undertaken with GPs and bereaved parents following the death at home of a child with cancer. GPs were contacted three months after the death of the child and the parents at six months. Thematic analysis of the transcriptions was undertaken.

**Findings** Parents described feeling abandoned at the transition to palliation when management of care transferred to the GP. Families did not perceive a seamless service of medical care between hospital and community. Where offered consultant contact was valued by families and GPs. Text and email were used by families as a means of asking the consultant questions. The GPs lacked role clarity where the consultant continued involvement in the care.

**Conclusions** The transition to palliation and the transfer of care to community services needs to be sensitively and actively managed for the family and the GP. Medical care between tertiary and

primary care should be seen as a continuum. Improving GP: consultant communication could aid role clarity, identify mechanisms for support and advice, and promote the active engagement of the GP in the care. Exploring opportunities for integrated consultant: GP working could maximise mutual learning and support and enhance care provision. The level, access and duration of ongoing contact between consultants and families/GPs require clarity.

## G179(P) LONG TERM FOLLOW-UP FOR PAEDIATRIC ONCOLOGY PATIENTS AT A PAEDIATRIC DEPARTMENT OF A GENERAL HOSPITAL

doi:10.1136/archdischild-2013-304107.191

<sup>1</sup>SM Murphy, <sup>2</sup>KM Husselbee. <sup>1</sup>Ninewells Hospital and Medical School, Dundee University, Dundee, UK; <sup>2</sup>Tayside Children's Hospital, Ninewells Hospital, Dundee, UK

### Aims

1. Establish how national Long Term Follow Up recommendations can be implemented locally in a paediatric department of a large general hospital.
2. Establish the number of patients who currently have an end of treatment summary in their notes.
3. Determine how many patients are attending appointments.
4. Identify if the appropriate patients are attending clinics.

**Methods** The medical notes for all patients appointed to attend the long term follow up clinic over the preceding two years were reviewed (93 patients).

It was noted whether each patient had an end of treatment summary present in their notes

Attendance at clinic over the past two years was noted. Patients were assigned into different groups according to the 'Therapy-based recommended levels of follow-up'.<sup>1</sup>

### Abstract G179(P) Table 1

Level	Treatment	Follow up	Frequency	Examples
1	Surgery alone, Low risk Chemotherapy	Postal or telephone	1–2 years	Low risk Wilms' LCH (single –system) GCH (Surgery only)
2	Chemotherapy, Low dose cranial irradiation (<24 Gy)	Nurse-led or primary care	1–2 years	Majority of patients (eg ALL)
3	Radiotherapy (> 24 Gy) Megatherapy	Medically supervised LFTU Clinic	Annually	Brain tumours, post BMT, Any stage 4 patients

### Results

The majority (91%) of patients did not have an end of treatment summary in their notes.

The majority of patients were in treatment 'level 2' (47%). Those in levels 2&3 will require long term medically supervised follow-up (nurse led or GP if level 2).

Attendance at clinic was noted & of those attending clinic, those with the best 'full time' attendance were those deemed to be 'level 2' patients. Followed by level 3 and 1 respectively.

**Conclusion** An 'End of Treatment Summary' should be implemented in the notes of all patients who have completed their treatment for childhood cancer.

Review current attendance of those deemed to be level 2 or 3 patients with the view to implementing a postal questionnaire in order to re-engage patients currently lost to follow-up.

### REFERENCE

1. Wallace, W Blacklay, A Eiser, *et al*. Developing strategies for long term follow up of survivors of childhood cancer. *BMJ* 2001;323:271-4.