### Abstract

**Identification of the Missing Cohort: Young People with Complex Neurodisability Who Are Difficult to Transition to Adult Services**

**Background**

Young people with complex long term conditions, severe learning disability, technology dependence and palliative care needs present specific additional challenges, making them difficult to transition to adult services. This cohort lacks a single unifying diagnosis making them difficult to identify.

**Aims**

To develop a reliable, reproducible method to identify young people of transition age with complex neurodisability.

**Method**

Lists of young people aged 14 or over from community physiotherapy, special school, specialist and palliative care clinics were merged. Antenatal mothers, patients who had not attended in the last two years or who had died were removed. The cohort was validated by community children’s nursing teams.

Patients were identified using the criteria:

- Severe or profound and multiple learning disability
- 3 or more specialist services
- Technology dependent
- Life threatening or life limiting condition
- Gross motor function measure 4 or 5
- Oxygen dependent

**Results**

56 young people were identified. Accurate information on learning disability, physical disability, technology dependence and oxygen use was inconsistently recorded in clinic letters. The majority of young people aged 18 or over but none aged under 16 had evidence of transition discussions. Several young people had clinic documentation indicating professional reluctance to transition to adult services because of a lack of appropriate services in the adult sector or a specific application to allow the young person to continue to access childrens services as there was no appropriate service in the adult sector.

20 (36%) were young people aged 18 years or older who were “stuck” or “delayed” in children’s services due to a lack of suitable target services in the adult sector. Approximately half of this group were oxygen dependent.

**Conclusion**

Young people of transition age with complex neurodisability can be identified from routine hospital data. However, the required information is not consistently recorded in any one place and the absence of information cannot be equated with the absence of need.

Transition to adult services for this cohort of patients is only being actively considered when the young person is 17 or 18 in contrast to other patients where a recognised transition pathway is in place (e.g. neuromuscular patients) where there was clear evidence of transition discussions from age 14.

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**Abstract Withdrawn**

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**Adolescent Females with Abdominal Pain: What Influences Sexual History Taking and Pregnancy Testing in A&E?**

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The ‘Saving Mothers’ Lives’ report found that between 2006–8 ectopic pregnancies accounted for over 1% of pregnancies in the UK, and 6% of maternal deaths. The accident and emergency (A&E) department is the first port of call for many women with symptoms of abdominal pain, collapse or vaginal bleeding. NICE recommends assessment of any women of a reproductive age must include consideration into whether symptoms are due to an ectopic pregnancy. We performed a six-month retrospective review of adolescents attending the A&E department with abdominal pain and examined factors influencing sexual history taking and urine pregnancy testing.

From April to September 2014, A&E notes of all female patients aged 13–16 years old presenting with abdominal pain were collated and screened using the computer system Symphony. Fifty patients fitted the selection criteria. The criteria assessing doctor’s department and grade was noted and information...
collected on presence of urine pregnancy test, sexual history taking, patient ethnicity and who, if anyone, accompanied the patient.

Of the fifty patients, half had a urine pregnancy test documented. Of the patients with documented urine pregnancy tests, A&E doctors performed this 73% of the time and paediatric team 25% of the time. Only 21% of Indian adolescents had a urine pregnancy test performed. Black patients had the highest rate of documentation of urine pregnancy test (83%). There did not appear to be a correlation between the percentage of urine pregnancy tests performed and person accompanying the patient. The surgical team documented the patient’s last menstrual period in 78% of cases, which was higher than the A&E department (62%) and paediatrics (53%). Only 11% of 16 year-old patients and 27% of 15 year old patients had sexual history taking documented.

There appears to be ethnic bias when performing a urine pregnancy test, but there is no correlation between rate of pregnancy tests, patient age and presence of an accompanying adult. These results highlight the need for improvement in sexual history taking and pregnancy testing in this patient group.

Results The preliminary interviews and sample (n = 53) have brought to light some interesting areas that can determine satisfaction (such as sufficient information given beforehand on gas versus drip induction and adolescent patients found the gown’s too revealing). It was also reassuring that current practices in paediatric anaesthetics are of a consistently high standard.

Conclusion We hope to create a digital version using an interface such as a tablet. It should be made clear that this is an ongoing project with exciting prospects and good potential for expanding into future areas of research. The focus is now to change practice.

**G154(P)**  
**TRANSITION OF PATIENTS WITH SICKLE CELL DISEASE – HOW CAN WE HELP? RESULTS OF A SURVEY OF ADOLESCENTS RECENTLY TRANSFERRED TO ADULT SERVICES**

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Background Recent reports suggest transition of young people with chronic diseases from paediatric to adult services is often untimely, ineffective, and poorly managed. Sickle cell disease (SCD) is typically diagnosed in childhood. Despite data reporting that rates of emergency admissions increase around the time of transition, few studies have reported experiences of patients undergoing transfer to adult services.

Aim We sought to survey adolescents with SCD who had recently transferred from paediatric to adult services in order to identify barriers to successful transition.

Methods Adolescents who had recently transferred from paediatric to adult services at a single site were identified. Patients were initially contacted by post with a letter and a copy of the validated Sickle Cell Disease Transition Questionnaire, assessing patients’ self-reported illness, functional skills, and disease management efficacy. Non-responders were followed up by a phone call and voice message after one and two months.

Results Thirteen adolescents were identified; six (46%) completed surveys. One was not receiving medical care in an adult setting and excluded. Four (80%) were aware of their haemoglobin type. The most common concerns regarding transfer to an adult care programme included unclear expectations [n = 4], ineffective communication [n = 4], and fear of being in a new environment [n = 3]. All those surveyed agreed that a dedicated transition programme would be useful to their health needs, and would assist in transferring care [n = 3], providing support [n = 4], and providing an opportunity to meet other adults with sickle cell disease [n = 2]. Participants varied in self-reported illness experiences, but four (80%) reported independently managing acute sickle and non-sickle disease medical problems before calling the doctor, except if severely unwell.

Conclusion Recently transitioned SCD patients placed a high importance on quality of information during transition and cultural independence, in particular from parents, during the transition of care from paediatric to adult services. Prior to implementation of a transition clinic, surveying users can help inform doctors and nurses of what to prioritise and how to effectively communicate relevant information.