

Arthriting: Exploring the relationship between identity and medicines use, and to identify the contribution of medicines and pharmacy services, for the care of young people with arthritis

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KEY FINDINGS AND RECOMMENDATIONS – December 2013

Aims and Methods:

Our aims were to (1) investigate the relationship between identity and medication use amongst adolescents with arthritis, and (2) to explore the role of pharmacy in delivering services to this group. During the project, young people (aged 11-15) with arthritis – and some parents – from the clinics at Birmingham Children’s Hospital NHS Foundation Trust (BCH) wrote blogs on our ‘Arthriting’ website, specially created for the project under the guidance of young people at BCH. These private blogs included thoughts about identity, the arthritis condition, medication and the use of health services. Young people and parents also had the chance to complete a survey about medication tasks and information-seeking. A case note review of 150 rheumatology clinic patients at BCH, and observation of the Young People’s Discussion Forum on the Arthritis Care website, added complementary data.

Key Findings

Twenty-one young people and six parents contributed blogs to the project. Key comments about **identity** included a largely positive self-image, and determination to achieve their goals, whilst realising that there were some limits to their physical and emotional endurance that manifested themselves at school and in social activities. They strove for ‘normality’, like any other young person, and expressed a need to communicate with other young people with arthritis to compare their experiences with someone who would understand their life context. The condition might be hidden from other people: choices about disclosure were complex. Comments about **the arthritis condition** included reflections on the physical and emotional demands of the condition, and changes since diagnosis. Pain was the most common symptom mentioned, but stiffness and tiredness were also common. Mood changes beyond the normal swings of adolescence were reported: parents showed their own emotional challenges seeing a loved one in pain. Comments about **medication and health services** included active decision-making regarding relative benefit and harm, and the side-effects of some medication (notably methotrexate). Most health providers were spoken of positively, but pharmacist references were limited and mixed. Parents were key players in the supply and administration of medicines. Transfer of responsibility varied in individual cases. Comments by young adults on the **discussion forum** highlighted anticipatory guidance topics, and the **case note review** identified recording gaps in topics such as the transfer of responsibility from parent to young person, and having a nominated community pharmacy.

Recommendations

- We must ensure that young people enjoy the same level of welcome and access to pharmacy services for people with long-term conditions as for other age groups;
- Pharmacists must consider their role in medicines optimisation for children and young people, both in terms of the technical supply of medicines under their guidance, and the provision of information;
- Pharmacists must consider the developmental and psychosocial factors that influence medicine-taking in adolescence, and be flexible about their approach to information-giving and adherence monitoring;
- Medicines Use Review, the New Medicines Service, and the Chronic Medication Service, should be employed to supply, and annually revisit, age- and developmentally-appropriate information for young people and families. These processes must be linked in with the rheumatology multidisciplinary team and other agencies;
- These activities must be underpinned by a research-informed training and education strategy that explores and develops pharmacists’ confidence and competence to engage with young people and families;
- A discussion forum for young people with arthritis, particularly aimed towards 11-15 year-old users and only open to this age group, should be developed to enable communication about a range of topics.