

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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Background:

Taking medicines as intended is difficult for everybody, but we know that young people going through adolescence have greater problems than adults and younger children. We do not know all of the reasons for this. One of the most important things that happen during the teenage years is the development of individual identities, which might not remain constant during this time and can be affected deeply by the diagnosis of a long-term condition. Young people with arthritis have extra challenges: they may feel different about their body image, and they may have complex medicine routines – including injections – that don’t fit with their ideas of ‘normal’, and that interfere with the activities that they would like to do. Their medicines can make them feel sick, can prevent them from drinking alcohol, and have to be taken even when they feel well – to keep them that way.

Aims, Objectives and Methods:

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. Data from each workstream contributed to meeting the study aims and objectives (Table 1).

Aims: To investigate the relationship between identity and medication use amongst adolescents with arthritis, and to explore the role of pharmacy in delivering services to this group.	
Objective	Relevant data from:
1. To investigate the relationship between identity and medication use amongst adolescents with juvenile arthritis.	<ul style="list-style-type: none"> • Blog entries • Discussion forum postings
2. To scope current patterns of care among young people with juvenile arthritis, and to map the current contribution of pharmacy and medicines to their treatment.	<ul style="list-style-type: none"> • Blog entries • Discussion forum postings • Online Survey • Casenote review • Scoping review
3. To scope current knowledge and practice of pharmacists regarding young people and juvenile arthritis.	<ul style="list-style-type: none"> • Scoping review

Table 1 – Contribution of each workstream to the project aims and objectives

Qualitative data from the blogs were analysed using directed content analysis¹ and corpus linguistic analysis². Data from the discussion forum postings were subject to directed content analysis only. Quantitative findings from the online survey and case note review were analysed using descriptive statistics.

A scoping review was undertaken of the Cinahl, International Pharmaceutical Abstracts, Medline, NELM, and Sociological Abstracts citation databases: papers had to be published since 2000 in English. We sought papers describing issues of the long-term conditions juvenile idiopathic arthritis (JIA), type 1 diabetes (IDDM) and inflammatory bowel disease (IBD). We also undertook key informant interviews.

¹ Hsieh H-F, Shannon SE. (2005) Three approaches to content analysis. *Qualitative Health Research*, 15(9): 1277-88.

² Adolphs S, Brown B, Carter R, Crawford P, Sahota O. (2004) Applied clinical linguistics: corpus linguistics in health care settings. *Journal of Applied Linguistics*, 1: 9-28.

Key Findings:

Blog and Survey Activity

Twenty-one young people and six parents contributed blogs to the project between August 2012 and January 2013. Among the young people, the average number of blogs posted was 8, and the range 1-36. Among the parents, the average number of blogs posted was 4, and the range 1-12. Ten young people and four parents completed the survey on the site. Most of the young people and parents who completed the survey (8 and 3, respectively) entered blogs over more than 4 weeks. This was notable as the survey did not go live until the beginning of the fifth week after registration. A summary of the results of the blog and survey activities has been organised here according to the three main areas of interest: identity, the arthritis condition, and the use of medication and associated health care services.

Identity

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.

The arthritis condition

Comments here 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.

Medication and health services

Comments here included active decisions which were made regarding relative benefit and harm, and the significant 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.

Case note review

Of the 150 cases, 128 young people were taking at least one medication. Those used most commonly were NSAIDs, followed by oral or subcutaneous methotrexate, and a similar number receiving etanercept. In none of their case notes was a local pharmacist identified, and half of them were registered with Healthcare at Home. No specific pharmacy issues were identified in the case notes, other than routine funding requests for subcutaneous and/or biologic therapies.

Self-management skills training are integral to transitional care planning. Unfortunately, in almost half of the case notes of young people on regular medication, it was unclear as to who was currently responsible for medication management. As for the Arthriting Blog study, the mother was the parent documented to be most involved in medication management. Self-management related topics were identified by a quarter of young people, with some young people in the late transition stage wanting further support regarding ordering and collecting prescriptions and booking appointments as well as calling the hospital themselves with their queries. Only a minority of young people wanted to know more about what their medications were for and their side effects which could reflect adequate knowledge already, a reluctance of young people to disclose their ignorance, or ambivalence towards the topic.

In view of the challenges anti-rheumatic medications present, it was surprising that adherence difficulties were only documented in one-quarter of the case notes. In those case notes where adherence difficulties were documented, the most common reason was related to side effects, reflecting the results of the Arthriting Blogs.

Arthritis Care Discussion Forum Postings

There were 45 postings noted from 28 young people, aged 16-25 years, in 14 different discussion threads between 1st October 2012 and 31st January 2013. Only 6 of the 28 young people declared an age of 18 years or less. The mean number of postings was 1.6 (range 1-5). The data in the Arthriting Blogs and discussion postings could not be compared directly, due to the different age ranges and hence developmental status. The young adults here exchanged a lot of information about University life, jobs and vocational training. The different social aspects of life, such as being able to wear adult high heeled shoes and to drink significant amounts of alcohol, were also highlighted. Twenty-one young people wrote about medicines, and there were specific discussion threads about methotrexate. We might be able to develop anticipatory guidance for clinicians that is useful during transition from adolescence to young adulthood from these findings.

Scoping Review

We found very few papers relating to pharmacists' engagement with young people. The only paper specifically linking pharmacy and young people with JIA was a CPD article in the *Pharmaceutical Journal* that was written by members of our team³. Papers in IDDM included specific insights that young people with IDDM struggled to find a role for the pharmacist, and had never had information from their pharmacies. Some young people thought there were, however, opportunities for pharmacy around signposting, referral and giving information about new treatments⁴.

Our young advisers at Arthritis Care led us to a paediatric rheumatology pharmacist in Belfast who had become integrated into the wider rheumatology team and who was recognised by young people as a valuable resource. She described the drivers for the service being the advent of biologic drugs and a risk assessment that had been done in her hospital. Over the course of 3 years she had established a place in the team. Another key informant from community pharmacy in Scotland, who had established a campus pharmacy, highlighted the opportunity within the Chronic Medication Service to conduct high risk medicine reviews for methotrexate with young people.

We have demonstrated links between identity, arthritis and medication, and considered the role of 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 members of the rheumatology MDT 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.

³ Gray N, Keady S, McDonagh J. (2010) Care in juvenile idiopathic arthritis (CPD article). *The Pharmaceutical Journal*, 285: 655-8.

⁴ Haugbolle LS, Devantier K, Frydenlund B. (2002) A user perspective on type 1 diabetes: sense of illness, search for freedom and the role of the pharmacy. *Patient Education and Counseling*, 47(4):361-8.