

Exploring the Perceived and Potential Medicines Optimisation Role of Pharmacy for Young People with Long-Term Conditions, Through the Case Study of Juvenile Arthritis

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Background:

Sparse research exists about the role of the pharmacist in the care of young people with chronic illness. In our previous ‘Arthriting’ study of the experience of young people using medication to treat juvenile arthritis, references to the pharmacist were rare – and those that did occur expressed frustration with technical aspects of getting prescription refills. The recent NICE guidance on medicines optimisation (NICE, 2015) emphasised that children, young people and adults using medicines were eligible to receive medicines optimisation services. The 2013 scoping document also emphasised that anywhere which received public funding, including independent contractor settings, will be venues for these services. Pharmacists may be unclear, however, whether key services to support medicines optimisation for young people can currently be employed.

Our scoping review in the previous ‘Arthriting’ study suggested that there were some examples of innovative and excellent practice, but that those professionals were isolated. Our Arthriting young person and parent blogs revealed that the profession more generally was largely invisible to them. Pharmacy needs to develop a cross-sector vision for the care of young people with long-term conditions in its communities, and actively promote it.

We have chosen juvenile idiopathic arthritis (JIA) as an exemplar of a long-term condition with multidisciplinary specialist care and complex medication. We believe that we can extend insights from the JIA exemplar to inform the pharmacy contribution to the care of young people with a wide range of long-term conditions. For example, we would expect the principles of having ‘young people friendly services’ would apply to the wider population, and young people’s priorities regarding services and the nature of their consultations with pharmacists are likely to be similar across a range of conditions. We have taken a UK-wide approach to this work, exploring devolution diversity.

Aim, Objectives and Methods:

Aim: To explore the current role, the potential role, and the needs of pharmacists to deliver services to young people with arthritis.

Objectives:

1. To scope current knowledge and practice of pharmacists regarding young people, including those with juvenile arthritis;
2. To explore the perceived and potential roles of pharmacists in the care of young people with juvenile arthritis, from the perspectives of community and hospital pharmacists, rheumatology health professionals and commissioners;
3. To inform the development of models of care, integrating pharmacy within the multidisciplinary team, in order to help young people with juvenile arthritis to optimise their use of medicines.

A sequential consensus-building study design was employed. Eighteen community and hospital pharmacists took part in four idea-generating focus groups across Great Britain. The thematic analysis of the verbatim transcripts from these focus groups underpinned a briefing for 15 stakeholders from the pharmacy and rheumatology community who took part in semi-structured telephone interviews. Statements of current and future roles supported by the combined thematic analysis of the verbatim focus groups and interview transcripts were presented to 13 pharmacists and 13 rheumatology staff members in three final discussion groups, where members individually - and as small multi-professional groups – rated and prioritized the ideas of the focus group pharmacists and stakeholder interviewees. In a final exercise, the pharmacists and rheumatology staff, as two separate groups, chose their ‘top 5’ current/future pharmacy activities to be prioritized in future policy and practice development.

Two advisory young people's group meetings were convened as part of our public and patient involvement strategy towards the end of the project; one in England and one in Northern Ireland. Twenty young people commented on the preliminary thematic analysis, and reported their broader experiences of their engagement with pharmacists.

Key Findings:

The development of communication skills with young people and parents among pharmacists

A strong theme throughout the groups was the need for pharmacists to develop skills in talking to young people and parents. Rheumatology staff emphasised that these extend beyond understanding confidentiality and consent – which pharmacists are becoming familiar with through provision of public health services such as emergency contraception. These skills included: gauging the level of engagement of the young person with conversations about medicines; managing the input of parents without excluding them, and tailoring information in a developmentally-appropriate way. Most pharmacists were not trained to do this, and many learned by experience. A major barrier identified to developing these skills in community was the lack of opportunities to engage with young people directly, as their parents tended to collect their prescriptions.

Information flow between sectors

Participants throughout the work, from all backgrounds, showed strong consensus about the need for better information flow between pharmacists in the community and pharmacists in the multidisciplinary hospital team. One area often cited was the sourcing of 'specials' by community pharmacy. It was apparent, however, that community pharmacists recognised their lack of knowledge about specialist areas like JIA and really wanted a pharmacy contact within the hospital to whom they could turn with other specialist clinical queries. Community pharmacists suggested that educational sessions run by local hospital pharmacists on such topics might then result in an ongoing relationship, with the hospital pharmacist as a known point of contact for future queries.

Pharmacists developing specialist expertise

Development of specialist expertise among pharmacists was a major discussion topic across all phases of the project. It was recognised that community pharmacists were unlikely to develop specialist knowledge about a range of areas. Although some might become a pharmacist with a special interest in one area, participants felt that it was more workable to develop the specialist role of the hospital pharmacist and then for community colleagues to be able to call on them for advice. It was recognised, however, that hospital pharmacists were often expected to cover a number of different paediatric specialties and this limited their integration into any multidisciplinary team (MDT).

Integration of hospital pharmacists within the rheumatology MDT

Despite the service pressures noted in the previous section, the specialisation discussions reached a broad consensus point that the hospital pharmacist should be better integrated within the rheumatology MDT. Some rheumatology stakeholders described innovative examples of working that were hitherto unknown to the project team, including a move to pharmacist prescribing in a rheumatology clinic. The project team stressed to rheumatology colleagues that we were not trying to 'sell' pharmacy when we discussed possible value from pharmacy input. Their reflections following this declaration, however, still resulted in their feeling that pharmacy input would be appreciated as a complementary role to clinical nurse specialists.

Pharmacists co-ordinating supplies of medicines

Despite the relatively low prevalence of juvenile arthritis in the average community pharmacy practice, there were specific reports of help that community pharmacists were giving in co-ordinating supplies of medicines. There was also a significant amount of discussion about the advantages and disadvantages of home care delivery services, nurse-led initiatives which were used widely for subcutaneous injection products. Many young people might be accessing medicines for their JIA through several channels; hospital / home care for the biologics or methotrexate injections, and their GP / community pharmacist for non-steroidal analgesia. Good communication was needed.

Empowerment of young people

One of the most interesting findings in the final discussion groups was that all the rheumatology teams prioritised the role of community pharmacy in developing ‘general healthcare system’ skills, whilst none of the pharmacy groups did so. These skills might include helping young people to understand and navigate the repeat prescription service in general practice, and helping them to minimise prescription charges as they move out of full-time education to work. It is unclear whether the pharmacists either assumed it was part of their core activity, or whether it did not seem aspirational enough as a role. There was also significant discussion across all phases of the project about the challenge in facilitating self-management among young people with regard to collection of prescriptions. Pharmacists in the focus groups – in both hospital and community settings - spoke at length about the challenge of knowing when a young person was ready to take on that responsibility. There was consensus that pharmacists had to revisit their prescription collection policies to enable relationships to develop with empowered young people.

Reflections of Young People in the Advisory Groups

As anticipated by the project team, young people with JIA in England did not have much engagement with pharmacists. If they needed information about their medicines, they reported that they would primarily ask a parent – who they recognised might then speak to a pharmacist or doctor on their behalf. Frustration about dispensing mistakes was reported. Young people agreed with themes that pharmacists did not know how to talk to young people, and tend to direct their conversation at parents; that community pharmacists did not have specialist knowledge about JIA, and that hospital pharmacists are too busy to talk. In Northern Ireland, however - where there is a dedicated paediatric rheumatology pharmacist – there were more reports of useful advice and engagement with hospital pharmacy. Awareness of, and confidence in, community pharmacy remained low.

Recommendations

For Pharmacists
<ul style="list-style-type: none">• Build communication skills and confidence with young people and their families• Understand the specific demands for a young person in the context of their health and health care and ongoing everyday life• Recognise that information from specialist teams may be needed as part of the clinical check• Build confidence in taking consent from young people in order to properly offer services like Medicines Use Review, and revise policies to allow collection of prescription medicines by ‘expert’ young people who have the necessary skills• Adopt the principles of ‘young people friendly services’ like the ‘You’re Welcome’ framework (England) and Walk the Talk (Scotland)• Involve the whole pharmacy team in this process
For the Wider Healthcare Team
<ul style="list-style-type: none">• Meaningfully integrate the pharmacist within your culture and processes• Routinely document a nominated community pharmacy where copies of information can be channelled, with the consent of the young person• Ensure that information flows to the nominated community pharmacist about specialist medicines• Ensure that community pharmacists have a point of contact in the hospital MDT for medication queries• Raise awareness with young people and families in transition programmes that the pharmacist is available to them, and can help them with general health system skills and their medicine queries
For Pharmacy / Healthcare Policymakers
<ul style="list-style-type: none">• Improve education for pharmacists (at undergraduate and post-qualification stages) about young people’s health, and how adolescent development impacts upon medicine-taking and decision-making• Include young people’s health in foundation and advanced practice frameworks• Give further guidance about consent for medicine-related activities to facilitate more engagement
For Young People and Families, and their Advocates
<ul style="list-style-type: none">• Think about pharmacy as a medicines information resource• Build a relationship with a local community pharmacist who can help you with your medicines• Agree a process for independent prescription ordering and collection with your pharmacy team