Meeting the needs of children who have parents with chronic inflammatory musculoskeletal diseases

How can children be adequately supported?

Chronic inflammatory musculoskeletal diseases, such as RA, SLE and AS, affect millions of people worldwide, many of whom either are of parenting age or will already be parents at the time of disease onset. Living with a chronic illness involves adapting to a physically changing body while re-negotiating established roles (e.g. mother or father). Evidence-based information delivered at appropriate times during the course of illness is important to help such individuals cope with these changes. Moreover, a parent’s rheumatic disease may have a major effect on the children (defined here as <18 years of age) and the family unit. Although we, and others, have examined the effects on adult patients in the family context [1, 2], no one has adequately established the effect from the children’s perspective, nor is there any information or education resources to help children cope with their parent’s illness. The type of information and format that would be useful to these children remain unknown, and many related research questions (such as the amount and degree of care that children and young people provide to patients and families) remain unanswered.

In studies about health-care experiences of women with SLE, it was apparent that the effect of the disease on the family unit was a major concern [3–5]. Children had to adapt to the fluctuating nature of the parent’s disease and tolerate being cared for by people outside the immediate family unit. They also took care of themselves, their mothers and other family members.

Patients felt that no educational resources or support were available to help them have a discussion with their children, particularly as a family, about what the children understood and their concerns; hence, these matters remained unresolved [4]. Health-care providers did not seem to communicate about these issues, mainly because the patients interacted with many different professionals and did not feel they knew any one person well enough to discuss their psychosocial concerns [5]. Children, particularly those of school age, are often effectively excluded from health-care interactions between mothers, their partners and health-care providers, and may be uncertain about how to raise questions.

The availability of educational materials would enable parents to facilitate family-based discussions. The timing of these discussions can be judged appropriately only by the individual family, as both the willingness to receive information about a parent’s illness and the ability to cope with it will vary from child to child. Within other disease groups (e.g. breast cancer), some information is available [6]. However, informing children about a parent’s diagnosis of a severe or chronic illness, or both, is mostly left to parents who are unprepared and unsupported [7]. Parents may over- or underestimate their children’s ability to understand about their illness and may believe the children to be more sophisticated in their understanding than they actually are. During the school-age years, children expand their understanding of specific illnesses, but their knowledge may be made up of both real and imaginary features, and they could attribute parental illness to their own actions [8]. It may be more appropriate to have specific individual counselling available, which raises questions about who provides such a service and what training would be necessary to support this.

Children who have a parent with a chronic illness may experience several serious consequences. For instance, a study explored the experiences and needs of such children living with a parent having mental health problems (e.g. depression) and found that children provided both emotional support and physical care for the parent [9], worried about the parent in the short and long term, were frightened to ask for help for themselves and were afraid to disclose the nature of their care responsibilities outside the family unit. These anxieties played a key factor in children’s inability to concentrate and their subsequent performance at school. People with chronic inflammatory rheumatic disease commonly experience feelings of depression and anxiety, thus the children may experience their parent with a low mood, as well as an intrusive chronic, fluctuating illness [10, 11].

In the UK, the Standards of Care for People with Inflammatory Arthritis and Connective Tissue Diseases developed by the Arthritis and Musculoskeletal Alliance (ARMA) suggest that at diagnosis, patients should have a full assessment that includes their psychosocial needs and families and carers should be involved in this process [12]. Ideally, patients should receive a tailored plan of care that provides information and education for both the patient and their carers. Although this process does not specifically address the needs of the children within the family unit, we argue that it should do so, as the quality of life within a family unit is inevitably a multidirectional process.

In the UK, children are increasingly encouraged to form partnerships with their health-care providers to facilitate informed decision making. As children who are deemed
competent are allowed to voice their opinion when determining treatment and quality of life issues for themselves, it seems reasonable that they should also be able to access appropriate information and education about a parent’s illness when that illness may also affect the disease-free child.

Furthermore, children should be encouraged to take part in research that asks them directly for their views about parental illness and its effects. Under the United Nations Convention on the Rights of the Child, a child has a right to be heard, their views must be taken equally into account in all matters that affect them and has the right to ‘seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child’s choice’ [13]. Children should play a key role in research that will develop educational materials and interventions that are designed ultimately for their benefit. Materials developed by adults for children may lack key components and hence produce less effective outcomes.

Exploratory research, particularly when trying to obtain useful and detailed information from children of varying ages, may require novel approaches. For example, our own research in this area will use multiple qualitative methodologies (e.g., interviews and visual data collection) that take into account the complex interactions within each family unit. Visual methods allow children to present their own data, and tell their own story about living with a parent with inflammatory musculoskeletal disease, may take into account different age ranges and interests and provide a unique insight into each child’s experiences [14].

By investigating both mothers and fathers with inflammatory musculoskeletal disease, it may be possible to compare the different effects on the family unit and children, while engaging a range of family units may be necessary to reflect the variation typical within modern society, and explore whether there are different effects and informational needs required by less traditional forms of family units. Engaging children of a wide age range will help tailor educational resources appropriately, and a variety of resources, such as books, leaflets, DVDs, electronic- and web-based resources, may be appropriate, which would depend on the developmental age of the children and their learning preferences.

Chronic inflammatory musculoskeletal diseases may have a major effect on patients, their partners and children, although no research has yet adequately established this effect from the children’s perspective. We are neither aware of the kind of information that would be useful to such children, nor the format (including counselling) in which they would like it delivered.

Research about parents’ and children’s perspectives on the experience and familial effect of having a parent with inflammatory musculoskeletal disease is long overdue, as is the need for relevant, evidence-based resource packages that inform, educate and reassure children.

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