

Editorial

Educating people with rare rheumatological conditions

Patients deserve better

A disease is considered to be rare if it has a population prevalence of < 5 in 10 000 [1]. Approximately 80% of rare diseases are genetic and present in childhood. The remaining 20% are acquired and present in adulthood. There are a number of rheumatic conditions that fall into this category, including most of the vasculitides and many of the connective tissue disorders. Rare diseases pose numerous educational challenges to both health-care professionals and patients; these can include ignorance of the condition among health-care professionals and patients, or relatives and friends who may never have heard of the condition. This leads to social and informational isolation because the patient has no one to turn to for advice. Increasingly, patients are turning to internet websites and chat rooms for advice, and some of these may be of poor quality [2].

It has long been recognized that patients with more common chronic rheumatic conditions, such as RA and SLE, benefit from access to high-quality educational provision [3]. Development of an education resource for patients with SLE has been found to have a positive effect on patients' levels of knowledge [4]. It has been demonstrated that people who clearly understand their illness and actively participate in their treatment plans have improved outcomes of care [5]; thus, educational programmes in common diseases have been shown to influence patient outcome and self-efficacy. For patients with a rare disease, there is much less educational provision. A survey carried out by Rare Disease UK on ~600 patients and families found that there were significant shortcomings in the education on how to live with a rare condition [6]. Of these 600, ~52% had not received sufficient information about their condition and 37% had no one to contact regarding questions about their illness [6].

We have previously shown in an exploratory qualitative study using a combination of focus groups and one-to-one interviews that patients with the chronic rare autoimmune disease ANCA-associated vasculitis (AAV) have significant informational requirements that need to be tailored to their specific needs and appropriate to their stage of illness. This study also showed that patients reported difficulty in assimilating information when acutely ill [7]. Those who join peer support groups, participate in research and gain access to novel therapies tend to fare better when coping with their disease [8].

A recent survey of patients with AAV conducted in both the UK and USA explored their priorities for information

and preferred method of delivery. Using a validated informational needs questionnaire, we demonstrated that the informational needs of vasculitis patients were high [9]. The most important areas for information provision were disease diagnosis and management, with psychosocial aspects of disease management given least importance. There was no difference in informational needs according to gender, age or disease duration. Comparison of the needs of AAV patients with breast cancer patients revealed that both required high levels of information, particularly regarding the areas of disease and treatment. For both vasculitis and cancer patients, information about psychological aspects was much less desired. The preferred method of information delivery was that information be provided by a doctor and supported by written material.

What then is the best method of delivering such information? In more common conditions, such as RA, there has been a vogue for the development of group education programmes. The rarity of conditions such as AAV makes this far more difficult except in the largest centres, where it is easier to run regular educational groups at a time when patients might need them. Patients will need information at the time of diagnosis as well as at regular intervals subsequently. Although groups are attractive as a means of delivering education to several people at the same time, it is not entirely clear from the experience in more common diseases, such as RA, that they are the most effective means of patient education [10]. Patients want information delivered by an experienced health professional, but for those with rare diseases, they often find that the right health professionals are scattered and may not be readily available. The development of networks within the National Health Service to care for adults with complex and rare rheumatic conditions might facilitate the development of educational resources around the central hubs.

Patient support groups are important because many provide detailed information in an accessible form, which can be downloaded for other family members to read. They also offer telephone support, which may be crucial for patients with rare conditions because they find it difficult to locate experienced people to talk to. Social media websites, such as health unlocked (<https://healthunlocked.com/>), provide a source of immediately available information derived from other patients. These sites also provide the opportunity to network with other patients, ask questions that may not have been discussed with a health professional and cross-check information so that the

consultation can be more effective for the patient. It is vital that the health professional signpost the patient to accurate sources of internet information and not leave the patient to wander aimlessly, finding unreliable information.

Patients with rare diseases deserve education of the same quality as that provided to patients with more common conditions. Where possible, this should be provided face to face by an experienced health professional with information appropriate to the condition and stage of disease. Patient support groups and social media have an increasingly important role in this provision.

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References

- 1 Commission E. Rare disease. http://ec.europa.eu/health-eu/health_problems/rare_diseases (4 November 2016, date last accessed).
- 2 Fisher JH, O'Connor D, Flexman AM, Shapera S, Ryerson CJ. Accuracy and reliability of internet resources for information on idiopathic pulmonary fibrosis. *Am J Respir Crit Care Med* 2016;194:218–25.
- 3 Ramos-Remus C, Salcedo-Rocha AL, Prieto-Parra RE, Galvan-Villegas F. How important is patient education? *Baillieres Best Pract Res Clin Rheumatol* 2000;14:689–703.
- 4 Young SP, Henderson E, Cheseldine DL *et al.* Development and assessment of a World Wide Web site for systemic lupus erythematosus patient information. *Lupus* 2002;11:478–84.
- 5 Ward MM, Sundaramurthy S, Lotstein D *et al.* Participatory patient–physician communication and morbidity in patients with systemic lupus erythematosus. *Arthritis Rheum* 2003;49:810–8.
- 6 Limb L, Nutt S, Sen A. Experiences of living with a rare disease. <http://www.raredisease.org.uk/documents/RDUK-Family-Report.pdf> (4 November 2016, date last accessed).
- 7 Mooney J, Poland F, Spalding N, Scott DGI, Watts RA. 'In one ear and out the other – it's a lot to take in': a qualitative study exploring the informational needs of patients with ANCA-associated vasculitis. *Musculoskeletal Care* 2013; 11:51–9.
- 8 Aymé S, Kole A, Groft S. Empowerment of patients: lessons from the rare diseases community. *Lancet* 2008;371:2048–51.
- 9 Mooney J, Spalding N, Poland F *et al.* The informational needs of patients with ANCA-associated vasculitis—development of an informational needs questionnaire. *Rheumatology* 2014;53:1414–21.
- 10 Grønning K, Skomsvoll JF, Rannestad T, Steinsbekk A. The effect of an educational programme consisting of group and individual arthritis education for patients with polyarthritis—a randomised controlled trial. *Patient Educ Couns* 2012;88:113–20.