Editorial

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How to manage patients' expectations in rheumatoid arthritis treatment

"Patients' expectations in relation to treatment are based on knowledge and previous experiences within the healthcare environment."

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The importance of the integrations of treatment expectations in patient care has received considerable attention in recent years, with a proliferation of newly developed instruments in the past decades [1]. This is a reflection, perhaps, of an acknowledgement that what patients hope for, expect or anticipate, which is an important predictor of treatment outcomes [2], exemplified, for example, by what significance patients put on medication [3].

Patients' expectations of illness, healthcare satisfaction and treatment [2,4] have been defined in a number of ways, for example, 'the anticipation that given events are likely to occur during, or as an outcome of healthcare' [2]. However, disagreement prevails, including in the measurement of its components.

The treatment of rheumatoid arthritis (RA), an inflammatory autoimmune disease, has radically changed over the last decades with the key aim from the clinicians' perspective to achieve rapid and sustained remission as measured by the Disease Activity Score [5]. In contrast, patients' individual goals tend to focus on reduced pain and fatigue, improved mobility, continuation of employment and help with psychological impacts, such as depression or anxiety [6]. The patients' goals may be achieved as a result of suppression of the Disease Activity Score, however, this is not uniform. Pain and fatigue often persist despite improved disease activity [7]. This observation serves to highlight that patients need holistic care that extends beyond simply immunosuppression. Patient-centered care delivered by multidisciplinary teams, incorporating education, psychological support, self-management advice, life style and exercise guidance are all recommended [8]. However, lack of resources means that such comprehensive care is infrequently available within the National Health Service of the UK. Data from the National Early Arthritis Audit due to be published in the autumn of 2015 will shed more light on this lack of optimal services for patients with RA. Typically, treatment consists mostly of disease-modifying antirheumatic drug (DMARD) monotherapy, combinations of DMARDs (with or without glucocorticoids) and DMARD–biologics combination following the 'treatment to target' approach with education and self-management support, provided ad hoc by the clinical care team [9]. One can argue that the mantra of 'treat to target' has too narrow a focus and does not truly align with patient-centered care.

An appreciation of how patients' expectations relates to RA care is important. Consider, for example, how clinicians might communicate the effectiveness of therapy. A practitioner may allude to a high probability to achieve remission when a patient is commenced on a biologic. If this information influences the patient's expectations, it may in turn sway concordance and thus lead to an improvement of success. In other fields of medicine, it has been observed that when clinicians set patients' expectations high, medication becomes more effective [10].

Patients' expectations in relation to treatment are based on knowledge and previous experiences within the healthcare environment [11]. The assessment of the probability

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of risk and benefit [4] is a subjective process that is substantially influenced by pre-existing health beliefs [2]. A number of theoretical models have been suggested to underpin patients' treatment expectations, most of which are based on the Social Learning Theory by Bandura [12] that considers why people behave the way they do within the context of their social environment. Expectations and beliefs that patients hold about their illness and treatment are conceptualized in the Common Sense Model of Illness [13] and the Necessity-Concerns Framework [14], respectively and have been shown to be related to a number of self-management behaviors and illness outcomes in a range of long-term conditions, including RA [15]. Typically, those who expect their illness to last a long time (even when symptoms are not currently present), report significant consequences to their lives (such as disability) and have confidence that their treatment is effective, tend to exhibit better treatment adherence, quality of life and disease control [16].

> "Being able to measure or elicit patients' expectations is an important first step in managing outcomes."

Crow *et al.* [17] go further and identified the three outcome expectations that are either treatment or patient related: beliefs that certain actions will achieve particular outcomes (e.g., taking the medication will reduce pain and stiffness; regular blood monitoring will minimize side-effects of treatment); process expectations: beliefs about the content and process of interventions (e.g., side effects of medication/detailed information and ongoing support by healthcare professionals); and self-efficacy expectations: beliefs in ones capabilities to organize and execute a certain course of action to achieve the required goal (e.g., exercising to keep mobile and reduce stiffness, pacing). The first two outcome expectations above are treatment related, while the latter is patient-related. This distinction may be helpful in consultations with patients and in the development or applications of treatment expectation scales [1,3].

Being able to measure or elicit patients' expectations is an important first step in managing outcomes. A systematic review of treatment and patient-related expectations in musculoskeletal disorders [1] included 24 scales across a range of musculoskeletal conditions, for example, self-efficacy scales for back pain, athletic injury, childhood arthritis, RA, knee surgery, etc.; but these lacked data on validity and reliability. Due to the wide range of diseases, it was difficult to compare the scales. The common sense model tells us that patients' expectations are likely to change over time as they assimilate new knowledge and experience of their illness. Therefore, multiple measurements are needed to assess the effect of an intervention that focuses on managing expectations. This is currently underway with a treatment expectation scale for new treatment [3] in a national longitudinal observational study of patients with early RA with 18 months follow-up, due to be completed this year.

Understanding the nature, formulation and expression of patients' expectations is essential to management and subsequently, satisfaction with the healthcare, professional–patient relationship and self-management of the illness. Patients are invited to be involved in making decisions about their healthcare that is informed by best practice and tailored to individual patient characteristics. Towle and Godolphin [18] describe a framework for both healthcare professionals and patients to facilitate shared decision-making, which includes elucidating and offering beliefs, concerns and expectations of treatment. Charles *et al.*'s model [19] takes this further and suggests that both parties take steps to build a consensus about preferred treatments and that an agreement is reached on the treatment to implement. Although in some cases this approach would be inappropriate, for long-term management of RA, which relies heavily on patient self-management, outcomes are improved when patients are actively involved in treatment decisions [20]. Managing and aligning expectations can be seen as problematic in RA due to frequent prescription changes and escalations needed to 'treat to target'. Inaccurate expectations can be modified through education and motivational interviewing [15,16] to promote shared decision-making.

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In summary, patients' expectations are infrequently taught as a clinical concept, yet it is now increasingly understood to be central to medical practice. The recognition that perceived outcomes of care differ greatly between individuals and learning how clinicians can capture and utilize such information, is a worthy goal for future research. Good decision-making requires both doctors/nurses and patient to be familiar with the evidence-based facts and to be able to weigh up the pros and cons of the alternatives. Inextricably linked to this is the understanding of the difference between awareness of medical information and the importance of patients' value-based judgement.

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