Subject: Qualitative study on perspectives of patients with inflammatory arthritis regarding cardiovascular risk

Table 1. Themes and Key Points That Emerged From Focus Groups of Patients with Inflammatory Arthritis

<table>
<thead>
<tr>
<th>Theme</th>
<th>Quotes from patients</th>
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<tbody>
<tr>
<td>Need for information about IA and medications</td>
<td>&quot;When I was first diagnosed, as far as the medications and the side effects and what I could expect. Like I said, everything I read was bad, and it didn’t—I’m probably going to take it the rest of my life, and you have to get your blood tested every three months to make sure everything’s looking good.&quot;</td>
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<tr>
<td>Lack of understanding regarding the association between CVD risk and IA</td>
<td>&quot;I never even thought about it. Had no idea that it would even affect my heart like that. I’m still in shock [laughter] that has to do with the arthritis.&quot;</td>
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AB1348

PERSPECTIVES OF PATIENTS WITH INFLAMMATORY ARTHRITIS REGARDING CARDIOVASCULAR RISK: A QUALITATIVE STUDY

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Background: Cardiovascular disease (CVD) is the most common cause of death among patients with inflammatory arthritis (IA) such as rheumatoid arthritis (RA), psoriatic arthritis (PsA) or ankylosing spondylitis (AS).

Objectives: To elicit perspectives of patients with IA to inform the design of a patient-centered intervention for a CVD risk reduction intervention.

Methods: This was a qualitative study guided by Bandura’s Social Cognitive Theory, placing special emphasis on knowledge about the relationship between arthritis and CVD as well as barriers and facilitators to receiving healthcare related to CVD risk such as screening and management for hyperlipidaemia. We recruited patients from a single academic center with either RA, PsA, or AS to participate in focus groups. Data were analyzed thematically.

Results: We conducted three focus groups with a total of 17 participants (5 participants in two and 7 participants in one of the focus groups) of mean age 56 (SD±7.7) years; 15 were women; 3 were on a statin; and 1 previously had a stroke. Barrier Themes 1-2: 1) Need for more information about arthritis, prognosis, and IA medications; 2) Lack of knowledge about how IA increases cardiovascular disease (CVD) risk; Facilitator Themes 3-5: 3) Lifestyle changes to reduce overall CVD risk; 4) Potential roles for peer coaches; and 5) Improving doctor-patient communication about IA, medications, and CVD risk. Patients expressed that improving Themes 2 and 5 could facilitate CVD screening.

Conclusion: Education about increased CVD risk could help activate patients with IA engage in CVD risk reduction strategies. Peer coaches appears to be a reasonable tool towards that goal.

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AB1349

PATIENT INVOLVEMENT IN BASIC RHEUMATOLOGY RESEARCH IS CHALLENGING BUT FEASIBLE. A 3 YEAR’S RESPONSIVE EVALUATION OF ADDED VALUE, PITFALLS AND CONDITIONS FOR SUCCESS

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Background: Empirical evidence for effective patient-researcher collaboration in basic research is lacking.

Objectives: To explore the feasibility and impact of patient involvement in basic rheumatology research and to identify facilitators and barriers.

Methods: Responsive evaluation of three years’ participatory research in which two formats were piloted: (1) patient participation in monthly team research meetings (first phase) and (2) patient-researcher partnerships in single research projects (second phase and follow-up). Data collection comprised surveys, interviews, training days, research team meeting reports and field notes. Regular reflective team meetings took place with active participant involvement. A qualitative analysis using thematic coding focused on impact, barriers and facilitators.

Results: In total 13 patient representatives (PRs) and 15 basic researchers participated. PRs experienced basic research as complex due to lack of understanding bio-molecular processes and the use of technical jargon. Their initial role was mostly listening, sometimes asking questions and sharing personal experiences. Informal communication was perceived as most beneficial. After three months the atmosphere relaxed and equal relationships emerged. Researchers’ motivation increased by talking with PRs, resulting in better understanding of disease burden on daily life and the societal impact of their research. They started to speak in lay language, which enabled PRs to appreciate the value of scientific rigour and why progress takes so much time. PRs obtained insight in the biological processes of their own disease. It inspired PRs to stay involved over a longer period. After 2 years, group-based consensus arose about the effectiveness of 1:1 patient-researcher contacts over patient participation in research team meetings. During follow-up, the number of partnerships increased from 2 to 11.