Patient Preference and Adherence

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ORIGINAL RESEARCH

Survey of a community-based infusion program for Australian patients with rheumatoid arthritis requiring treatment with tocilizumab: patient characteristics and drivers of patient satisfaction and patient-perceived benefits and concerns

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Background: Tocilizumab is an effective therapy for patients with moderate to severe rheumatoid arthritis that is administered by infusion over one hour every 4 weeks. The community-based infusion (ACTiv) program was introduced to Australia in August 2010 to provide accessible and convenient treatment for patients with rheumatoid arthritis who require tocilizumab. The primary objectives of this study were to determine the characteristics of patients in the ACTiv program, patient satisfaction, and patient-perceived benefits and concerns with the ACTiv program, and drivers of patient satisfaction and patient-perceived benefits and concerns.

Methods: A voluntary self-administered survey was given to all 608 patients in the ACTiv program between January 27, 2011 and March 31, 2011.

Results: A total of 351 surveys were returned completed, giving a response rate of 58% (351/608). Most patients in the ACTiv program were women aged 40–64 years, with a mean disease duration of 13.7 years and moderate disability, who had been in the ACTiv program for ≥5 months. Most patients (88%, 302/342) were either very satisfied or satisfied with the ACTiv program and believed that they were very unlikely or somewhat unlikely to switch from the ACTiv program (64%, 214/335). The most important benefit was the reassurance of receiving treatment from a trained nurse in a professional medical environment (33%, 102/309). The most important concern was the fear of side effects (48%, 134/280). The main drivers of patient satisfaction and patient-perceived benefits and concerns of patients were health profile, previous medication experience, and length of treatment time in the program.

Conclusion: The ACTiv program is used by patients of various ages, family life situations, and locations. Patient satisfaction with the program is high, which enables patients to benefit from long-term use of tocilizumab.

Keywords: arthritis, rheumatoid, infusions, intravenous, patient satisfaction, survey, health, tocilizumab

Introduction

Rheumatoid arthritis is a chronic inflammatory, autoimmune disorder that can lead to long-term joint damage. In Australia, about 400,000 people are affected by rheumatoid arthritis.[1] First-line therapy for patients with the disease usually involves at least one synthetic disease-modifying antirheumatic drug (DMARD), most commonly methotrexate,[2] in combination with analgesics. However, synthetic DMARDs alone

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are not effective in a considerable proportion of patients.[3] In patients with moderate to severe rheumatoid arthritis, biologic DMARDs (eg, abatacept, adalimumab, certolizumab pegol, etanercept, golimumab, infliximab, rituximab, tocilizumab), which are administered by subcutaneous injection or intravenous infusion, may improve clinical outcomes and slow disease progression.[4] In Australia, many rheumatologists work in private practice and may not be affiliated with a hospital, hence biologic DMARDs that require regular intravenous infusion are often administered via community-based[5,6] or home-based[7] infusion programs.

Tocilizumab is a humanized anti-interleukin-6 monoclonal antibody that is an effective monotherapy[8] or combination therapy[9] for patients with moderate to severe rheumatoid arthritis. Tocilizumab is prepared just before use and administered by infusion over one hour every 4 weeks.[10] In Australia, tocilizumab is administered by qualified and trained nurses in community-based infusion centers or in hospital settings. A community-based infusion (ACTiv) program sponsored by Roche Products Pty Limited (Dee Why, NSW, Australia) was introduced to Australia in August 2010 to provide accessible and convenient treatment for patients with rheumatoid arthritis who require treatment with tocilizumab. Patients in the ACTiv program have access to a choice of infusion centers, are assigned a dedicated, trained infusion nurse who monitors each infusion, and can have their medication delivered to the infusion center. All patients eligible for treatment with tocilizumab are also eligible for the ACTiv program.

The primary objectives of this study were to determine the characteristics of patients in the ACTiv program, patient satisfaction and patient-perceived benefits and concerns with the ACTiv program, and the drivers of patient satisfaction and patient-perceived benefits and concerns. The secondary objective of the study was to assess decision-making in the treatment of rheumatoid arthritis.

Materials and methods

Study design

This survey was given to patients in the ACTiv program between January 27, 2011 and March 31, 2011. Ethics approval was obtained from the Bellberry human research ethics committee (Bellberry Limited, Dulwich, SA, Australia) before the survey commenced. The survey was conducted in accordance with relevant guidelines and the code of Professional Behavior of the Australian Market and Social Research Society.

The survey was given to the patients along with medication delivery, or given to the patients by a program nurse (if the patients did not have their medication delivered). However, it was not determined if the survey was delivered to all patients. The survey was voluntarily self-administered and patients were given the option to return an uncompleted survey. Uncompleted and completed surveys were sealed in an envelope and returned to the Pollinate research company (Surry Hills, NSW, Australia) by post.

Study population

All patients in the ACTiv program were invited to complete a survey (there were no exclusion criteria). All patients in the ACTiv program are adults (≥18 years), have a diagnosis of moderate to severe rheumatoid arthritis, have previously had an incomplete response or no response to synthetic DMARDs, and are eligible for tocilizumab subsidized by the Australian pharmaceutical benefits scheme. The ACTiv program provides monthly administration of tocilizumab (Actemra®, Roche Products Pty Limited) by qualified and trained nurses in community-based infusion centers.

Survey information

The survey was designed by the author. Roche Products Pty Limited, Pollinate, and state infusion nurse managers provided input into the administration of the survey. The survey used lay terminology, was completed using written answers, and was anonymous. The survey was designed to be completed in less than 20 minutes.

The survey was provided as online supplementary data, and was divided into the following four parts: demographic profile, health profile, rheumatoid arthritis treatment history, and ACTiv program experience. Information on demographic profile and history of rheumatoid arthritis treatment was collected using questions that requested information directly or selection of an answer(s). Health profile information was collected using the Stanford Health Assessment Questionnaire-Disability Index (HAQ-DI),[11] which has been validated in patients with rheumatoid arthritis.[12] The HAQ-DI assesses a patient's level of functional ability.[13] The HAQ-DI is scored on a scale of 0 (no disability) to 3 units (completely disabled). A HAQ-DI score of 0 to 1 indicates mild to moderate disability, a score of 1 to 2 indicates moderate to severe disability, and a score of 2 to 3 indicates severe to very severe disability. Information on experience with the ACTiv program was collected using questions that requested information directly or questions that rated satisfaction (very dissatisfied, dissatisfied, neither satisfied or dissatisfied, satisfied, very satisfied), likelihood (very unlikely, somewhat unlikely, neither unlikely nor likely, somewhat likely, very likely), and

relevancy (highly irrelevant, somewhat irrelevant, neutral, somewhat relevant, highly relevant).

Survey outcomes

The primary outcomes were demographics, health profile, treatment history, patient satisfaction, and patient benefits and concerns. The secondary outcome was decision-making.

Statistical analysis

To overcome any effect of the order of questions, the surveys were produced with responses in different orders. Batches of surveys were printed on different colored paper that indicated to the response coder which numeric code frame to use for data entry. A code book for all closed questions was created at the end of the survey and a code frame for all open questions was created after 80% of the surveys had been received. A single person entered the data from all surveys. The surveys were cross-checked to ensure that response scales have been interpreted in the correct direction. A completed survey was defined as a survey where at least 80% of the responses were valid and complete. A refusal was defined as the return of an uncompleted survey.

All data collection and statistical analyses were conducted by Pollinate. Data were summarized using descriptive statistics and were grouped by patient characteristics. Differences between means were assessed using a *t*-test with a two-tailed α level of 0.05. Differences between proportions were assessed using a *z*-test with a two-tailed α level of 0.05. Missing data were not imputed for the analyses. All analyses were conducted using IBM SPSS Statistics Version 19 (New York, NY).

Results

At the end of the survey period there were 608 patients in the ACTiv program and 95 infusion centers staffed by 82 qualified and trained nurses.

Survey response rate

A total of 351 surveys were returned completed, giving a response rate of 58% (351/608). In addition, 85 uncompleted and 15 partially completed surveys were returned. The remaining 157 surveys were not returned.

Demographic profile of patients

Patients in the ACTiv program represented a variety of ages, family life situations, and locations (Table 1). Because of the nature of the population, the demographics of the patients who did not return the survey could not be characterized.

Health profile of patients

The mean duration of rheumatoid arthritis for patients in the ACTiv program was 13.7 years (standard deviation 10.3 years). Patients in the ACTiv program had moderate disability (Tables 1 and 2) and most patients had mild or moderate overall HAQ-DI scores (Table 1). There was a significantly lower percentage of males (5%, 3/66) than females (20%, 55/276) with a severe overall HAQ-DI score ($P < 0.05$). The relative disability of patients in the ACTiv program was influenced by many demographic characteristics (Table 2).

History of rheumatoid arthritis treatment

Sixty-five percent (212/328) of patients had been in the ACTiv program for ≥5 months. The remaining patients (35%, 116/328) had been in the program for 1–4 months (note, patients must demonstrate a response to treatment, based on assessment after about 3 months of treatment, in order to continue government-funded treatment).

Most patients had been treated previously with one or more biologic DMARDs, although 20% (71/351) of patients had not been treated previously with a biologic DMARD for rheumatoid arthritis (Table 1). About half of the patients had been treated previously with a subcutaneous biologic DMARD and some had been treated previously with an intravenous DMARD (Table 1).

Patients typically received concomitant treatment for rheumatoid arthritis while they were in the ACTiv program. The most common concomitant rheumatoid arthritis treatment was synthetic DMARDS, taken by 66% (232/351) of patients and the most common synthetic DMARD was methotrexate, taken by 56% (197/351) of patients. A small percentage (13%, 46/351) of patients took tocilizumab without additional synthetic DMARDs, steroids, or nonsteroidal anti-inflammatory drugs.

Patients who had been in the ACTiv program for ≥5 months took significantly less concomitant rheumatoid arthritis treatment than patients who had been in the ACTiv program for 1–4 months. Fewer patients who had been in the ACTiv program for ≥5 months took synthetic DMARDs (61% [130/212] versus 77% [89/116], $P < 0.05$), in particular methotrexate (51% [108/212] versus 67% [78/116], $P < 0.05$), compared with patients who had been in the program for 1–4 months. Significantly more patients who had been in the ACTiv program for ≥5 months did not use concomitant synthetic DMARDs, steroids, or nonsteroidal anti-inflammatory drugs, compared with patients who had been in the program for 1–4 months (15% [32/212] versus 7% [8/116], $P < 0.05$).

Table 1 Demographic and health profile of patients in the community-based infusion program

Characteristic	Total N = 351	Female n = 282	Male n = 66
Mean age, years (SD)	55.4 (13.7)	54.9 (14.2)	57.8 (11.3)
18–39 years, % (n)	11 (39)	14 (38)	1.5 (1)*
40–64 years, % (n)	60 (210)	58 (162)	71 (47)*
65+ years, % (n)	28 (99)	29 (81)	27 (18)
Partner status, % (n)			
Does not live with partner	39 (135)	40 (112)	33 (22)
Lives with partner	61 (212)	60 (168)	67 (44)
Highest level of education, % (n)			
Year 9 or below	16 (55)	14 (40)	23 (15)
Year 10	19 (67)	21 (58)	14 (9)
Year 11 or 12	17 (58)	17 (47)	17 (11)
Diploma or certificate from a college or TAFE	28 (97)	27 (75)	32 (21)
Degree or diploma from a university	16 (56)	16 (46)	15 (10)
Postgraduate degree	4 (14)	5 (14)	0 (0)
Employment status, % (n)			
Works part-time or full-time	36 (126)	34 (96)	46 (30)
Does not work, 18–39 years	37 (129)	39 (108)	30 (20)
Does not work, 65+ years	26 (91)	27 (75)	24 (16)
Household annual income before tax, % (n)			
Under $20,000	8 (28)	8 (23)	8 (5)
$20,000–$49,999	19 (64)	17 (47)	24 (16)
$50,000–$79,999	16 (55)	16 (46)	14 (9)
$80,000–$99,999	6 (20)	6 (16)	6 (4)
$100,000–$149,999	6 (21)	6 (18)	5 (3)
$150,000 or more	4 (15)	4 (12)	5 (3)
Social security benefit/pension	20 (70)	20 (56)	20 (13)
I don't know/I don't wish to divulge	22 (78)	22 (64)	20 (13)
Location, % (n)			
State capital city, <20 km from CBD	23 (78)	25 (69)	14 (9)
State capital city, >20 km from CBD	19 (67)	18 (51)	24 (16)
Regional center or large town	36 (125)	36 (100)	36 (24)
Rural area	22 (76)	21 (58)	26 (17)
Median distance, km (min, max)			
From infusion center	10 (0, 300)	10 (0, 300)	10 (1, 150)
From nearest hospital	10 (0, 70)	10 (0, 60)	10 (1, 70)
Treatment history with biologic DMARDs, % (n)			
No biologics previously used	20 (71)	20 (57)	20 (13)
Used 1 biologic before tocilizumab	32 (111)	31 (87)	35 (23)
Used 2 biologics before tocilizumab	27 (94)	26 (73)	32 (21)
Used 3 or more biologics before tocilizumab	21 (75)	23 (65)	14 (9)
Treatment administration history, % (n)			
No IV or SC treatment	20 (71)	20 (57)	20 (13)
Used IV only or IV and SC treatment	28 (100)	30 (86)	20 (13)
Used SC treatment only	51 (180)	49 (139)	61 (40)
Time in the ACTiv program, % (n)			
1 to 4 months	35 (116)	36 (95)	35 (21)
5 or more months	65 (212)	64 (170)	65 (39)
Overall adjusted HAQ-DI score[a], mean (SD)	1.2 (0.7)	1.3 (0.7)	1.0 (0.7)
Mild score (HAQ-DI 0 to 1), % (n)	36 (124)	34 (94)	44 (29)
Moderate score (HAQ-DI 1 to 2), % (n)	47 (163)	46 (127)	52 (34)
Severe score (HAQ-DI 2 to 3), % (n)	17 (58)	20 (55)	5 (3)*
Ability to carry out everyday activities score[b], mean (SD)	2.4 (1.0)	2.4 (1.0)	2.1 (1.0)*
Pain score in the past week[c], median (min, max)	45 (0, 100)	50 (0, 100)	30 (0, 100)
Health score in the last week[c], median (min, max)	50 (0, 100)	50 (0, 100)	50 (0, 100)

Notes: *$P < 0.05$ compared with females; [a]score range of 1 to 3; [b]score range of 1 to 5; [c]score out of 100.

Abbreviations: CBD, central business district; DMARD, disease-modifying antirheumatic drug; HAQ-DI, Health assessment questionnaire – disability index; IV, intravenous; max, maximum; min, minimum; SC, subcutaneous; SD, standard deviation.

Table 2 Health profile of patients (by group) in the community-based infusion program

Patient group	Mean RA period (years)	Mean overall HAQ-DI score[a]	Ability to carry out everyday activities[b]
Total	13.7	1.2	2.4
Female	14.1	1.3	2.4
Male	11.6	1.0*	2.1*
18–39 years	11.2	1.1	2.0
40–64 years	13.2	1.2	2.3
≥65 years	15.7	1.3	2.6†
Does not live with partner	14.2	1.3	2.4
Lives with partner	13.4	1.2	2.3
Works	11.7‡	0.8‡	1.9‡
Does not work, 18–64 years	14.2	1.4	2.6
Does not work, ≥65 years	15.5	1.3	2.6
ACTiv program 1–4 months	12.0	1.3	2.4
ACTiv program ≥5 months	14.1	1.2	2.3
No biologics	12.3	0.9	2.1
Used 1 biologic	13.3	1.2	2.4
Used 2 biologics	13.9	1.3§	2.5
Used 3 or more biologics	15.4	1.4§	2.5

Notes: *$P < 0.05$ compared with females; †$P < 0.05$ compared with younger age groups; ‡$P < 0.05$ compared with does not work groups; §$P < 0.05$ compared with no biologics; [a]score range of 1 to 3; [b]score range of 1 to 5.
Abbreviations: ACTiv, community-based infusion; HAQ-DI, Health Assessment Questionnaire-Disability Index; RA, rheumatoid arthritis.

Some patients discontinued rheumatoid arthritis treatment after being in the ACTiv program. Discontinuation of concomitant rheumatoid arthritis treatment was higher for patients who had been in the ACTiv program for longer. For example, synthetic DMARD use was discontinued by 44% (93/212) of patients who had been in the program for ≥5 months compared with 25% (29/116) of patients who had been in the program for 1–4 months ($P < 0.05$).

Patient satisfaction with program

Overall, most patients (88%, 302/342) were either very satisfied or satisfied with the ACTiv program. Only 1.2% (4/342) of patients were dissatisfied with the ACTiv program. Gender, age, partner status, employment status, decision-making views, and treatment history did not influence patient satisfaction with the ACTiv program. Significantly more patients in the ACTiv program for ≥5 months were very satisfied or satisfied with the program compared with patients in the program for 1–4 months (91% [193/211] versus 81% [88/108], $P < 0.05$). Patients with a low overall HAQ-DI score were significantly more likely to be very satisfied or satisfied with the ACTiv program than patients with medium or high overall HAQ-DI scores (96% [118/123] versus 83% [131/157] and 86% [49/57] respectively, $P < 0.05$).

Patients generally believed that they were very unlikely or somewhat unlikely to switch from the ACTiv program (64%, 214/335). Only 9% (31/335) of patients believed that they were somewhat likely or very likely to switch from the ACTiv program. The likelihood of patients switching from the ACTiv program was influenced by the duration the patients had been in the program (1–4 months, 49% [52/106]; ≥5 months, 70% [144/206], $P < 0.05$), treatment history with biologic DMARDs (for patients previously treated with at least three biologic DMARDs 59% [42/71] were very unlikely or somewhat unlikely to switch compared with 79% [53/67] of patients who had not previously received any biologic treatment, $P < 0.05$), and overall HAQ-DI score (for patients with a low HAQ-DI score 77% [92/120] were very unlikely or somewhat unlikely to switch compared with 55% [84/154] of patients with a medium HAQ-DI score, $P < 0.05$).

Benefits and concerns perceived by patients

The most important benefit of the ACTiv program that was most frequently selected was reassurance of receiving treatment from a trained nurse in a professional medical environment (benefit 1, 33% [102/309] of patients, Table 3). Other highly rated benefits included no need to self-administer injections (benefit 2), overall convenience (benefit 3), and the fact that Actemra is a newer agent compared with some of the alternatives (benefit 4). Demographic and health factors (gender, age, employment status, duration on program, history of biologic DMARD treatment, overall HAQ-DI score, administration method, partner status, location) did not influence patient selection of the most important benefits of the ACTiv program.

Table 3 Patient-perceived benefits of the community-based infusion program that were selected as most important

Benefit of the ACTiv program	% (n) Patients[a] n = 309	Mean relevance score[b] (SD)
1. Reassurance of receiving treatment from trained nurse in a professional medical environment	33 (102)	4.6 (0.9)
2. No need to self-administer injections	20 (62)	4.0 (1.3)
3. Overall convenience	9 (29)	4.2 (1.1)
4. Actemra[c] is a newer agent compared with some other alternatives	9 (29)	3.7 (1.2)
5. Proximity of infusion center	8 (24)	4.1 (1.2)
6. Regular contact with nurse	5 (14)	4.3 (1.0)
7. No need to pick up prescriptions or prepare drugs	5 (14)	4.3 (1.1)
8. Appeal of infusion center environment compared to alternatives such as hospital or specialist's office	4 (11)	3.9 (1.3)
9. Frequency of visits	4 (11)	4.0 (1.2)
10. Opportunity to meet up with other RA patients at the infusion center	1 (4)	2.8 (1.3)
11. Infusion time spent relaxing, eg, catching up on magazines	0 (1)	3.4 (1.3)

Notes: [a]Percentage of patients who selected this benefit as the single top benefit of the program; [b]patients were asked for the relevance of the possible benefits to their own experience with the ACTiv program. Score range from 1 (highly irrelevant) to 5 (highly relevant); [c]Actemra is the brand name of tocilizumab.
Abbreviations: RA, rheumatoid arthritis; SD, standard deviation; ACTiv, community-based infusion.

All benefits were considered to be relevant to the patient's own experience with the ACTiv program (Table 3, relevance scores). However, patients' perceptions of relevance varied with demographic and health factors. Patients who had been in the program for longer considered regular contact with a nurse (benefit 6, Table 3) to be more relevant than patients who had been in the program for a shorter period (mean relevance score 4.1 versus 4.4, $P < 0.05$). In addition, patients who had not previously used a biologic DMARD considered that the reassurance of receiving treatment from a trained nurse in a professional environment (benefit 1), regular contact with a nurse (benefit 6), no need to pick up prescriptions or prepare drugs (benefit 7), and the appeal of an infusion center environment (benefit 8) to be more relevant than patients who had used intravenous or intravenous and subcutaneous biologic DMARDs, respectively (mean relevance scores 4.8, 4.5, 4.6, and 4.2 versus 4.4, 4.1, 4.1, and 3.5, respectively, $P < 0.05$).

The most important concern with the ACTiv program that was most frequently selected was the fear of side effects (concern 1, 48% [134/280] of patients, Table 4). Overall, the concerns noted in the survey were considered by patients to be less relevant to their own experience with the ACTiv program compared with the benefits (relevance scores Table 4 versus Table 3). Some demographic and health factors (duration on program, overall HAQ-DI score, location) appeared to influence the selection of the most important concerns with the ACTiv program. The factors considered

Table 4 Patient-perceived concerns with the community-based infusion program that were selected as most important

Concern with the ACTiv program	% (n) Patients[a] n = 280	Mean relevance score[b] (SD)
1. Fear of side effects	48 (134)	3.2 (1.3)
2. Distance from nearest infusion center	9 (25)	2.6 (1.5)
3. Actemra is a newer agent compared to some other alternatives[c]	8 (22)	2.7 (1.3)
4. Total treatment time of 1.5–2 hours substantially longer than some alternatives	7 (20)	2.4 (1.2)
5. Loss of flexibility and independence associated with self-injecting	7 (20)	2.4 (1.4)
6. Inconvenience of travelling to and from the infusion center	6 (16)	2.4 (1.4)
7. Anxiety about the infusion procedure	4 (10)	2.2 (1.2)
8. More frequent treatments	3 (9)	2.2 (1.2)
9. Lower appeal of infusion center environment compared with alternatives such as hospital or specialist's offices	3 (9)	2.3 (1.3)
10. Lower reassurance due to lack of doctor or specialist at treatment	3 (8)	2.0 (1.1)
11. Overall inconvenience	2 (5)	2.4 (1.3)
12. Feel less in control of treatment	1 (4)	2.1 (1.1)

Notes: [a]Percentage of patients who selected this benefit as the single top concern with the program; [b]patients were asked for the relevance of the possible concerns to their own experience with the ACTiv program. Score range from 1 (highly irrelevant) to 5 highly relevant; [c]Actemra is the brand name of tocilizumab.
Abbreviations: SD, standard deviation; ACTiv, community-based infusion.

to be of most concern in patients who had been in the ACTiv program for a shorter period compared with a longer period were Actemra being a newer agent (concern 3: 1–4 months, 13% [12/92] versus ≥ 5 months, 5% [9/168], $P < 0.05$) and lower reassurance due to the lack of a doctor or specialist being present during treatment (concern 10: 1–4 months, 5% [5/92] versus ≥ 5 months, 1% [2/168], $P < 0.05$). In addition, anxiety about the infusion procedure was of more concern for patients with a high overall HAQ-DI score compared with patients with a medium score (concern 7: 12% [5/42] versus 1% [1/123], $P < 0.05$). Distance from the nearest infusion center was of most concern to patients from a rural area (concern 2: 20% [11/56]).

The most common answers when patients were asked "what would you say to other rheumatoid arthritis patients about the ACTiv program" were "good staff/service" (by 40% [122/306] of patients), "convenient and easy" (by 33% [100/306] of patients), and "satisfied/happy" (good/great/excellent, by 24% [72/305] of patients).

Decision-making about treatment

Overall, most patients (77%, 264/344) thought that the final decision about treatment for their rheumatoid arthritis should be a joint decision between the patient and their rheumatologist, rather than by their rheumatologist alone (18%, 61/344) or the patient alone (5%, 19/347). The patients' thoughts about who should make the final decision regarding treatment of rheumatoid arthritis was influenced by gender, age, employment status, and previous rheumatoid arthritis treatment administration method. Patients who reported that the final decision about their treatment for rheumatoid arthritis should be made by the rheumatologist were mostly male (males versus females: 27% [17/64] versus 16% [44/280], $P < 0.05$), older (65 years versus 40–64 years: 28% [27/98] versus 14% [29/207], $P < 0.05$), and did not work (older patients who did not work versus worked: 28% [25/91] versus 13% [16/126], $P < 0.05$) Patients who reported that the final decision about their rheumatoid arthritis treatment should be a joint decision between the patient and their rheumatologist were mostly female (female versus male: 80% [225/282] versus 64% [42/66], $P < 0.05$) and those who had previously used subcutaneous biologic DMARDs (previous use versus no previous use: 80% [144/180] versus 66% [47/71], $P < 0.05$).

The final decision to join the ACTiv program was mostly (66% [230/348] of patients) made as a joint decision between the patient and their rheumatologist, rather than by their rheumatologist alone (30%, 104/348) or the patient alone (4%, 14/348). The older the patient, the more likely it was that the rheumatologist made the decision to enter the ACTiv program (18–39 years, 8% [3/39]; 40–64 years, 28% [58/207]; 65+ years, 43% [43/99]).

Discussion

Understanding the characteristics of patients and their beliefs is advantageous to rheumatologists when making decisions about treatment of rheumatoid arthritis. This is the first study to investigate patient characteristics, patient satisfaction, drivers of patient satisfaction, and patient-perceived benefits and concerns in a community-based infusion program for delivery of a biologic DMARD to patients with rheumatoid arthritis. Overall, this study found that patients in the ACTiv program for tocilizumab in Australia were very satisfied with the program; reassurance of receiving treatment from a trained nurse was the most frequently reported important benefit of the program and, to a lesser extent, fear of side effects was the most frequently reported important concern. The main drivers of patient satisfaction and patient-perceived benefits and concerns identified were health profile, previous medication experience, and length of treatment time in the ACTiv program.

Although the patients in the ACTiv program represented a wide range of patients, in general, most were women aged from 40–64 years with a mean disease duration of 13.7 years and moderate disability. In addition, most patients had received treatment with a biologic DMARD before receiving tocilizumab. This demographic profile reflects the general population of patients with rheumatoid arthritis treated with biologic DMARDs and is consistent with the profile of patients with rheumatoid arthritis who are registered for tocilizumab treatment in Europe.[14] Although the demographic characteristics of patients in the ACTiv program were not found to be drivers of patient satisfaction or patient-perceived benefits and concerns, they did influence patients' perceptions of decision-making about their treatment. In general, most patients in the ACTiv program were involved, with their rheumatologist, in decision-making about their treatment. This finding is in contrast with a British study of patients with rheumatoid arthritis taking antitumor necrosis factor-α therapy, which found that only 7% of patients were jointly involved with their rheumatologist in decision-making about the treatment of their rheumatoid arthritis.[15] The differences in treatment decision-making between the current study and the British study may reflect differences in the study population, socioeconomic factors, or culture.

The most important benefit of the ACTiv program that was identified most frequently in this study was the

reassurance patients gained from receiving treatment from a trained nurse in a professional medical environment. This is similar to an Italian study of patients with rheumatoid arthritis on antitumor necrosis factor-α therapy,[16] which highlights the importance of direct interaction between patients and professionals. Other benefits included no need to self-administer injections, overall convenience, and the newness of Actemra compared with alternative treatments. Although some benefits were considered to be more relevant (reassurance of receiving treatment from a trained nurse in a professional environment, regular contact with a nurse, no need to pick up prescriptions or prepare drugs, and the appeal of an infusion center environment) than others by patients who had been in the program for longer or who had previously received treatment with a biologic DMARD, no demographic or health factors were identified that influenced patients' selection of the important benefits of the program.

In contrast with the perceived benefits of the ACTiv program, the level of concern among patients in the program was relatively low, with important concerns being rated less relevant than important benefits. As would be expected, the most common concern of patients in the program was fear of side effects. Patients receive information regarding the potential side effects of their treatment from their doctors, their previous experience with other medications, and from other sources (eg, social groups, Internet sites). Hence, this finding highlights the importance of counseling patients about how to avoid side effects and what patients should do if side effects occur. The factors that appeared to drive patients' concerns were the duration of time in the ACTiv program, severity of disability (HAQ-DI), and living distance from the infusion center. More patients who had been in the ACTiv program for a shorter period of time rated the newness of Actemra and the lower reassurance due to the lack of a doctor or specialist at treatment as important concerns, more patients with greater disability rated anxiety about the infusion procedure as an important concern, and more patients from rural areas rated their living distance from the infusion center as an important concern. These findings further highlight the role of the trained nurse in the ACTiv program in providing the appropriate counseling and reassurance required with regard to any potential effects of treatment or the infusion procedure, and will assist rheumatologists when counseling patients with regard to their treatment options.

An important finding from this study was that increased access to tocilizumab through the ACTiv program enabled patients to achieve the benefits of long-term treatment with tocilizumab. Patients who had been in the ACTiv program for ≥5 months used less concomitant rheumatoid arthritis medication and had a higher rate of discontinuation of concomitant rheumatoid arthritis medication. In particular, discontinuation of concomitant steroid use was high in patients who had been in the ACTiv program for longer (26% rate of discontinuation), which is consistent with the findings from a long-term study of tocilizumab treatment in patients with rheumatoid arthritis from Japan (32% rate of discontinuation).[17] In addition to the benefits of long-term treatment, the length of time that a patient had been in the ACTiv program was a driver of patient satisfaction. This may in part be because patients who were in the program for longer experienced an improvement in health (data not presented) and, as described earlier, because of the influence of duration of time in the program on patient-perceived benefits and concerns.

The strength of the survey is that the results are directly relevant for the rheumatologists in Australia who are caring for patients with rheumatoid arthritis and will assist in decision-making and counseling of patients with regard to their treatment options. Given the success of community-based infusion programs, there may be a move to more community-based care for patients with rheumatoid arthritis.[18] Hence, the findings in this study may be applicable to infusion programs underway for other biologic DMARDs or other drugs. The survey had a response rate of 58%, which meets the expectations of surveys in general[19] and patients were representative of those with rheumatoid arthritis who receive treatment with biologic DMARDs. However, because not all patients responded to the survey, it is possible that the results are not representative of all patients in the ACTiv program. In addition, when applying the findings of this study to clinical practice, clinicians should consider that the survey was not validated in pretesting analysis, did not measure clinical outcomes, and did not compare the ACTiv program with other methods of tocilizumab infusion or other biologic DMARDs.

In conclusion, the ACTiv program in Australia is used by patients of various ages, family life situations, and locations. Patient satisfaction with the program is high and enables patients to benefit from long-term treatment with tocilizumab. The most important perceived benefit of the program was the reassurance patients gain from receiving treatment from a trained nurse in a professional medical environment. Other important benefits included overall convenience and removal of the need to self-administer injections. Although perceived concerns about the program were rated less relevant than benefits, the most common concern was a fear of side effects.

This study suggests that factors such as health profile, previous medication experience, and length of time on treatment, rather than demographic or decision-making factors, may be drivers of patient satisfaction and patient-perceived benefits and concerns with the ACTiv program.

Disclosure

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