PATIENTS' SATISFACTION WITH THE RHEUMATOLOGY DAY CARE UNIT

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Abstract

Background: Patients receiving biological therapies are regularly evaluated and monitored at rheumatology day care units (RDCU). Despite patients' satisfaction with the delivered care and the relationship between the patient and the multidisciplinary team being acknowledged as important aspects to ensure adherence to therapy, factors associated with them have not been investigated so far.

Objectives: To evaluate patients' satisfaction with the functioning of the RDCU and to identify the factors associated with the level of satisfaction.

Methods: An anonymous questionnaire was administered to all patients with rheumatoid arthritis (RA) or spondyloarthritis treated with biological drugs and followed at the RDCU at Hospital Garcia de Orta, Almada, Portugal. Satisfaction was measured using a visual analogue scale (0-100, 0 meaning completely unsatisfied, 100 meaning completely satisfied). Further information was collected on socio-demographic variables, physical conditions of the RDCU, waiting time, satisfaction with the role of medical, nursing and administrative staff (satisfaction level with their friendliness, question answering, care delivery, privacy during consultation, clarity in the information given, which was then transformed into a composite score, 0-20). Factors associated with satisfaction were studied by univariable followed by multiple linear regression to adjust for potential confounders.

Results: In total, 150 patients were included in the study (mean age 50.6 ± 13.7 years, 64% female, 62% RA, mean disease duration 10.6 ± 6.1 years). The majority of patients attended the RDCU for more than three years and 57% received subcutaneous therapy. The mean level of satisfaction with the RDCU was 81.9 ± 17.9. Multivariable analysis showed that intravenous therapy (β 6.13, 95% confidence interval – CI 0.71-11.55), physician score (β 2.28, 95%CI 1.20-3.35) and increasing levels of satisfaction with the room temperature (β 5.64, 95%CI 3.06-8.21) and waiting time (β 25.53, 95%CI 8.17-42.89, for a very good vs non-acceptable waiting time) were positively associated with the level of satisfaction, while the nursing score was inversely associated.

Conclusions: Patients were overall very satisfied with the functioning of the RDCU. Waiting time, satisfaction with the physician role, room temperature and intravenous therapy were the main factors positively associated with the level of satisfaction.

Keywords: Patient Satisfaction; Day care; Biological Therapy; Portugal.

Introduction

Patients' satisfaction has been widely investigated in health care research. Many authors consider patients' satisfaction as an indicator of quality of care from the patients' perspective[1-4] and it is increasingly considered an important component of comprehensive chronic disease management[5]. The importance of patients' satisfaction as a measure of quality is based in two main principles: 1) patients are an essential source of information on how a health care service works; 2) patients' perspective is increasingly being valued when planning and evaluating services[1,6,7].

The assessment of patients' satisfaction through satisfaction surveys is nowadays the preferred method for valuing the perspective of patients about the health care provided[8]. Findings from several studies established the importance of the relationship between satisfaction and both the physical environment and the interpersonal components of a health unit[9,8]. Empathy and assurance with the health care team, which mainly represent interpersonal communication, were identified as having a strong influence on the patients' willingness to come back to the hospital[9]. This, in turn,

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may also represent a better adherence to the treatment plan and disease monitoring, particularly important in chronic conditions.

In the last decade there has been a paradigm shift in the approach to chronic inflammatory rheumatic diseases, in part thanks to a better understanding on the etiopathogenic mechanisms of the diseases, but also the emergence of new and more efficacious drugs. With the widespread use of biological drugs in various inflammatory rheumatic diseases, including rheumatoid arthritis (RA) and spondylarthritis (SpA), rheumatology departments have adapted to this reality, being it essential to ensure high levels of quality in the care delivered. Patients treated with biological drugs are evaluated in a standardized way in dedicated clinics, usually in the environment of a RDCU. At Hospital Garcia de Orta, in Almada, the RDCU is an integrated outpatient unit at the Department of Rheumatology, where every day patients with chronic systemic diseases are followed, in particular RA, SpA (including ankylosing spondylitis, psoriatic arthritis and undifferentiated spondylarthritis), juvenile idiopathic arthritis, Behçet's disease, systemic lupus erythematosus, progressive systemic sclerosis, Sjögren syndrome, systemic vasculitis or idiopathic inflammatory myopathy treated with biotechnological drugs. The biological therapies, administered subcutaneous (SC) or intravenously (IV), are expensive drugs with some well-known risks that justify close monitoring and rigorous evaluation of the risks and benefits. All patients taking these drugs, either administered IV (Infliximab, Rituximab, Abatacept, Tocilizumab), or SC (Etanercept, Adalimumab, Anakinra), are regularly monitored at the RDCU. When patients are stable, the clinical and laboratory evaluations are carried out every 12-16 weeks.

The quality of health services provided by multidisciplinary teams and the patient's relationship and empathy with those, are essential issues to increase the security and the patient's compliance to therapy, which are a key to therapeutic success[10-12]. For these reasons, it is important to know the level of the patients' satisfaction, both with to the physical aspects of our RDCU, but also with the provision of health care by the various elements of the health team, in particular physicians, nurses and administrative staff.

The purpose of this study was to evaluate the level of patients' satisfaction with the functioning of the RDCU and to investigate the factors associated with this level of satisfaction.

Methods

Study Population

We conducted a cross-sectional study that included patients with RA and SpA, treated with biological drugs and regularly followed at the RDCU at HGO. All patients with the above-mentioned diseases and assessed at the RDCU during the first semester of 2010 were invited to participate and no further eligibility criteria were applied. The 150 patients who participated in the study were assessed using an anonymous questionnaire.

Patients' satisfaction with the rheumatology day care unit

The overall patients' satisfaction regarding the RDCU was assessed using a visual analogue scale from 0 (completely unsatisfied) to 100 (completely satisfied). We evaluated various dimensions of patients' satisfaction with regard to the physical conditions of the RDCU (room's size, decoration and temperature) and to the role of the physician, nursing and administrative staff, using Likert scales (ranging from 0 to 4, from unsatisfied to very satisfied). The delivery of care by physicians and nurses was evaluated with respect to their friendliness and attention, response to questions, way how provided care was delivered, privacy during care and clarity of the information provided. The administrative service was classified for the kindness, availability/attention, speed/efficiency and clarity of the information provided. For each professional, we calculated an overall score reflecting the level of patients' satisfaction with the performance of the health professional. In the case of the level of patients' satisfaction with the rheumatologist's performance, this score was designated as physician score (ranging from 0, patient unsatisfied with the performance of the physician in all five evaluated dimensions to 20, patient very satisfied with the performance of the physician in the five dimensions evaluated). The nursing score was constructed similarly, ranging between the same values. The administrative score, also built in a similar way, ranged from 0-16, reflecting the four dimensions evaluated.

Factors possibly associated with patients' satisfaction with the rheumatology day care unit

We also evaluated demographic and clinical factors

possibly associated with the level of patients' satisfaction with the RDCU. Demographic factors assessed were age, gender, marital status, number and relationship to the people with whom the patient lived and educational level. With regard to clinical factors, we collected information on the rheumatic disease diagnosed, disease duration, type of biological drug used, follow-up time at RDCU and disease activity. The disease activity was assessed by the Disease Activity Score with 28-joint assessment (DAS28)[13], in the case of RA, and the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)[14], in the case of SpA.

Patients were also asked about some aspects related to the RDCU that could be associated with their level of satisfaction, including the distance from home to the RDCU, travel method, accompanying in the visit to the RDCU, ease of access to the RDCU from the main entrance of the hospital, waiting time and adequacy of the physical environment for the purpose of the RDCU. The waiting time was rated from 0 to 3, where 0 corresponded to "not acceptable", 1 "reasonable", 2 "good" and 3 "very good". The RDCU team recommends to patients to contact the RDCU by telephone, in case of doubt or appearance of any new event, so that an urgent evaluation can be considered. In this context, patients were asked whether they were aware of this possible telephone contact, as well as their previous experience with contact to the RDCU in an urgent situation, in case they had any.

Statistical Analysis

First, a descriptive statistical analysis was undertaken, in which the categorical variables are expressed as frequencies and the continuous variables in the form of mean ± standard deviation.

The administrative score was converted to vary from 0 to 20, to be more easily comparable to the results obtained for the physicians' and nurses' scores.

In order to identify factors associated with the level of the overall patients' satisfaction with the RDCU, univariable linear regression analyses were undertaken between the level of the overall patients' satisfaction (0-100) and the demographic, clinical and physical factors related to the RDCU previously described.

Factors with a p-value < 0.1 were subsequently included in a model of multiple linear regression analysis (backwards method) until the best final model was obtained and which is presented. Statistical analysis was performed using Stata SE version 11 and a significance level of 5% was assumed.

Results

The study included 150 patients, with a mean age of 50.3 ± 13.7 years, being 64% female (Table I). Sixty-two percent of the patients had a diagnosis of RA, the remaining had SpA (ankylosing spondylitis/undifferentiated spondylarthritis). The average rheumatic disease duration was 10.6 ± 7.9 years. Considering only the patients with RA, the mean disease duration was 10.3 ± 7.0 years and 11.2 ± 9.1 years for the patients with SpA.

Most patients were followed at the RDCU for more than five years, and 43% of the patients were on intravenous therapy (Infliximab, Rituximab, Abatacept or Tocilizumab), while the remaining were treated with subcutaneous therapy (Adalimumab, Etanercept or Anakinra).

Most patients (46%) lived at a distance from the hospital lower than 15 Kms, 31% at a distance of over 25 Kms, the vast majority of the patients (75%) travelled to the hospital by car and 65% on their own (Table II).

Table I. General characteristics of the population

	Mean ± SD or % (n = 150)
Age (years)	50.3 ± 13.7
Gender (% female)	64
Marital status (% married)	73
Educational level (%)	
• read and write only	3
• 4th grade	30
• 9th grade	18
• 12th grade	19
• graduation	21
Follow-up time in RDCU ≥ 3 years (%)	62
RA (%)	62
Rheumatic disease duration (years)	10.6 ± 7.9
IV therapy (%)	43
DAS 28 (n=93)	3.75 ± 1.39
BASDAI (n=57)	2.38 ± 1.33

SD – standard deviation; RA – rheumatoid arthritis; IV – intravenous; DAS28 – disease activity score with 28-joint assessment; BASDAI – Bath Ankylosing Spondylitis Disease Activity Score

Table II. Characterization of aspects of the RDCU

	Mean ± SD or % (n = 150)
Distance home – hospital (%)	
• 1-15 km	46
• 15-25 km	19
• >25 km	31
Easy access to the RDCU (%) (yes/no)	85
Patients' satisfaction with the waiting time (%)	
• not acceptable	2
• reasonable	27
• good	42
• very good	29
Room appropriate for the RDCU (%) (yes/no)	84
Patients' satisfaction with the room size (%)	
• satisfied	26
• reasonably satisfied	24
• very satisfied	22
Patients' satisfaction with the room decoration (%)	
• satisfied	43
• reasonably satisfied	26
• very satisfied	24
Patients' satisfaction with the room temperature (%)	
• satisfied	41
• reasonably satisfied	20
• very satisfied	35
Knowledge of possible telephone contact in case of urgency (%) (yes/no)	92
Efficiency of telephone contact in case of urgency (%) (yes/no)	99
Previous access to the RDCU in an urgent situation (%) (yes/no)	35
Easy access to the RDCU in urgent situation (%) (yes/no)	98

RDCU – rheumatology day care unit; SD – standard deviation

When asked about ease of access to RDCU from the entrance of the hospital, 85% confirmed it was easily accessible. Of the 23 patients (15%) who reported a not easy to access to the RDCU from the entrance of the hospital, the reasons given were in 39% the difficulty in parking the car, in 30% a long waiting time for the lifts and in 30% the long distance between the RDCU and main entrance.

The waiting time was considered good by 42% of the patients; 29% found it very good and 27% reasonable; 2% found it not acceptable.

When asked about the adequacy of the RDCU room for its purpose, 84% of the patients agreed it was adequate. The level of satisfaction with the room size was fairly satisfactory for 24% of the patients and very satisfactory for 22%. As for the decoration of the room, 43% of the patients were satisfied, 26% fairly satisfied and 24% very satisfied. Regarding the room temperature, 41% showed satisfaction, 20% were fairly satisfied and 35% very satisfied.

One hundred and thirty-eight patients (92%) admitted having knowledge of the possible telephone contact to the RDCU in case of urgency, and 99% of the patients confirmed that when they needed help, the telephone contact with the RDCU did solve their problems. We also wanted to know if patients had used the RDCU in case of an urgent situation and 52 patients (35%) said yes. Of those patients, 98% reported to be easily attended at the RDCU in these situations.

The average overall patients' satisfaction level with the RDCU, considering all its functioning, was 81.91 ± 17.91, on a scale from 0 to 100, where 0 meant completely unsatisfied and 100 completely satisfied.

The levels of patients' satisfaction with the different dimensions in delivery of care by the physician, nursing and administrative staff are in Tables III, IV and V. The mean physician score was 16.53 ± 4.27 and the nursing score was 17.70 ± 3.54. The administrative score obtained the mean value of 16.71 ± 4.86. The privacy of patients during their consultation, either with the physician or nurse, was the aspect evaluated as the least satisfactory for patients: only about 40% of the patients were very satisfied with this aspect, comparing with a frequency of above 70% for the other aspects evaluated. The various aspects of delivery of care with respect to the nursing team were identified as very satisfactory, with more than 85% of the patients being very satisfied. With respect to the performance of the administrative staff, the speed and efficiency in the service was the least satisfactory aspect.

The disease activity of patients with RA, assessed using the DAS28, had an average score of 3.75 ± 1.39. Sixty-two of the 93 patients (67%) had a DAS28 equal or superior to 3.2, so they had active

Table III. Physician Score

	Unsatisfied	Little satisfied	Satisfied	Fairly satisfied	Very satisfied
Friendliness and attention	0%	1%	13%	8%	78%
Response to questions	0%	1%	14%	13%	71%
Way how provided care was delivered	0%	1%	13%	6%	80%
Privacy during care	6%	15%	19%	25%	35%
Clarity of the information provided	1%	0%	16%	12%	70%

Table IV. Nursing Score

	Unsatisfied	Little satisfied	Satisfied	Fairly satisfied	Very satisfied
Friendliness and attention	0%	0%	7%	2%	91%
Response to questions	0%	0%	8%	6%	86%
Way how provided care was delivered	0%	0%	6%	1%	92%
Privacy during care	5%	13%	16%	22%	44%
Clarity of the information provided	0%	0%	9%	5%	86%

Table V. Administrative Score

	Unsatisfied	Little satisfied	Satisfied	Fairly satisfied	Very satisfied
Kindness	0%	1%	15%	15%	69%
Availability/attention	1%	1%	17%	15%	67%
Speed/efficiency	0%	1%	19%	21%	59%
Clarity of the information provided	0%	1%	19%	14%	66%

disease. Thirty-one of the 93 patients evaluated with the DAS28 (33%) had low disease activity (DAS28 < 3.2), and of these, 17 (17 of 93 patients = 18.3%) met criteria for remission (DAS28 < 2.6).

Disease activity of patients with SpA was assessed by the BASDAI and had an average score of 2.38 ± 1.33. Six of the 57 evaluated patients (11%) with BASDAI had active disease (BASDAI>4).

Factors associated with the level of patient satisfaction with the RDCU

The factors that were associated with patients' level of satisfaction were identified by a univariable linear regression analysis, followed by multivariable regression (Table VI). The best final model, adjusted for gender, age and main diagnosis, identified the use of intravenous treatment (β 6.13, 95% CI 0.71 – 11.55), the satisfaction with the room temperature (β 5.64, 95% CI 3.06 – 8.21), the satisfaction with the physician performance (β 2.28, 95% CI 1.20 – 3.35) and the evaluation of the waiting time as factors with a positive association with the level of satisfaction.

Taking the patients that evaluated the waiting time as not acceptable as a reference, the patients who considered the waiting time very good had a global level of satisfaction 25 times higher (β 25.53, 95% CI 8.17 – 42.89), while the patients who considered the waiting time as good had a satisfaction level 24 times higher (β 24.04, 95% CI 7.50 – 40.59).

There was an inverse relationship between the overall patients' satisfaction and the nursing score (β -1.71, 95% CI -2.91 – -0.50). There was no statistically significant association (either in the univariable regression) between the overall level of satisfaction and the following variables: disease

Table VI. Univariable and multivariable linear analysis

Variables	Univariable Analysis β (95% CI)	Multivariable Analysis β (95% CI)
Gender (female vs male)	-6.76 (-12.74; -0.79)	0.42 (-5.56; 6.39)
RA (yes/no)	-6.80 (-12.68; -0.92)	-2.50 (-8.70; 3.71)
Age (years)	-0.04 (-0.25; 0.18)	-0.05 (-0.23; 0.14)
IV therapy (yes/no)	9.81 (4.15; 15.46)	6.13 (0.71; 11.55)
Satisfaction with the room temperature (0-4)	8.56 (5.90; 11.22)	5.64 (3.06; 8.21)
Physician score (0-20)	1.85 (1.20; 2.51)	2.28 (1.20; 3.35)
Nurse score (0-20)	1.11 (0.22; 1.99)	-1.71 (-2.91; -0.50)
Reasonable vs not acceptable waiting time	28.09 (9.11; 47.07)	19.21 (2.65; 35.78)
Good vs not acceptable waiting time	35.35 (16.61; 54.09)	24.04 (7.50; 40.59)
Very good vs not acceptable waiting time	45.34 (26.41; 64.27)	25.53 (8.17; 42.89)
Satisfaction with the room size (0-4)	5.10 (2.92; 7.25)	*
Satisfaction with the room decoration (0-4)	7.24 (4.40; 10.09)	*
Administrative score (0-20)	0.85 (0.24; 1.46)	*
Travel to the RDCU by car vs walking	27.89 (7.27; 48.51)	*
Travel to the RDCU by bus vs walking	23.04 (1.47; 44.61)	*
Travel to the RDCU by train vs walking	26.22 (2.74; 49.70)	*

* The variable was not selected during the multivariable analysis (p ≥0.05)
CI – confidence intervals; IV – intravenous; RA – rheumatoid arthritis; RDCU – rheumatology day care unit.

duration, marital status, educational level, number of people with whom the patient lived, ease of access to the RDCU, satisfaction with the adequacy of the room, knowledge about the possibility of telephone contact with RDCU in an urgent situation, the follow-up time at the RDCU, the distance from home to RDCU, the travel to the RDCU with a companion and the disease activity (DAS28 and BASDAI).

The multivariable linear regression analysis was repeated, including in the model the individual variables that were part of the physician and the nursing scores, and the results were similar, with the same variables in the final model (except for intravenous therapy) and the regression coefficients being in the same order of magnitude (results not shown). From the individual variables from the physician and nursing scores, the only one that remained in the final model was the satisfaction with the friendliness of the doctor (β 12.95, 95% CI 9.54 – 16.37, in the univariable analysis and β 2.28, 95% CI 1.20 - 3.35, in the multivariable analysis).

Discussion

Overall, patients are very satisfied with the functioning of the RDCU. The average level of satisfaction was 81.91 ± 17.91, on a scale from 0 to 100, where 0 meant completely unsatisfied and 100 completely satisfied.

The main factors which have been shown to be associated with the overall level of patients' satisfaction were: the waiting time, global satisfaction with the medical delivery of care, intravenous therapy and the temperature of the room, all with a positive association with the level of patients' satisfaction. Satisfaction with the nursing care showed an inverse relationship with the level of overall satisfaction.

The results of this study are consistent with the literature, though sparse in this area. Cleary and McNeil[15] identified the characteristics of health care providers or organizations that result in personal care as factors associated with higher levels of satisfaction. No other similar studies analyzing factors associated with patients' satisfaction with respect to their treatment were found.

The results of several studies have shown the importance of the interpersonal component of the delivery of care on patients' satisfaction[16,17]. A similar result was obtained in our study, with regard to overall medical assistance and more specifically to the most valued by patients: the physician's friend-

liness and this was the only item, among the different ones evaluated on the delivery of care by health professionals, with a statistically significant association with the overall patients' level of satisfaction.

With respect to patients' satisfaction with the performance of the nursing staff, we obtained an inverse association with the level of overall patients' satisfaction. As a possible explanation, we consider the fact that this health professional does not yet have a recognized significant impact on the assessment and treatment of rheumatic patients, such as the physician's expertise actually has. This result enhances the fact that, in Portugal, there is still a long way to go. There is much room for improvement in the nursing training and skills development for the treatment of rheumatic patients and for the assertion of the specialized nurse role so that this health professional is truly recognized in their working environment and their contribution has a positive impact on the approach to the patient.

Eijk-Hustings *et al.*[18], on behalf of the European League Against Rheumatism (EULAR) nursing task force, developed ten recommendations for the role of the rheumatology nurse in the management of patients with chronic inflammatory arthritis. These recommendations may provide a basis for emphasising and optimising nursing care in order to contribute to a more standardised level of professional nursing across Europe. These recommendations underline the nurses' role to be an interface between the patient and other members of the multidisciplinary team. As a result of the availability of new treatment options and organisational developments, the role of the nurse has undergone significant changes over the last decades. However, there are still striking difference between and within countries, mainly due to differences in legal regulations, educational background of the nurses, and funding issues related to overall health care provision[18].

One of the items most valued by patients was the waiting time. It is understood that the time spent by patients in their hospital visits is necessary to be spent on other activities and it is not pleasant for the patient to have to wait. In this regard, one of the concrete proposals resulting from this project consists precisely in the attempt to optimize the organization of the RDCU, in order to reduce the waiting time of patients.

In order to plan specific measures in an attempt to maximize the patients' level of satisfaction with the RDCU, it would be important to identify not only factors which were associated with the overall level of satisfaction, but essentially factors with a causal relationship. In this sense, studies with a longitudinal design could assess this particular point. The identification of factors with a possible causal relationship with the overall level of satisfaction would enable the planning of specific measures to improve this aspect, so important for the patient and the success of the therapy, a key objective for all professionals involved in treating these patients. Later, it would also be interesting to follow prospectively patients and investigate the different outcomes of patients with different levels of satisfaction with the care delivered.

Conclusion

Overall, patients are very satisfied with the functioning of the RDCU. Patients more satisfied with the waiting time for evaluation at the RDCU, under intravenous therapy and more satisfied with the room temperature and with the delivery of care by the rheumatologist revealed a higher level of overall satisfaction. Satisfaction with the performance by nurses was inversely associated with the overall level of satisfaction, which probably reflects a failure to recognize the important role of nurses in the management of chronic rheumatic diseases.

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