

Patients' perceptions on shared decision making during prescription of subcutaneous biological drug treatments for inflammatory arthritis: The RHEU-LIFE survey

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Abstract

Objectives: The aim of this study was to explore the preferences of patients with rheumatic diseases and their perceived experience regarding participation in shared decision making (SDM) when they were prescribed a subcutaneous (SC) biological drug.

Methods: A printed survey was handed to 1,000 patients with inflammatory rheumatic diseases treated with SC biological drug. The survey included closed questions about preferences regarding decision making and about patients' experience when they were prescribed an SC biological drug. Descriptive statistics were performed with stratification by patient profiles, using chi-square for comparisons between groups.

Results: A total of 592 surveys were received (response rate 59.2%, mean age 51.7 years, 57.6% women). Some 28.2% of patients reported preferring to take part in treatment selection, a percentage that was higher in younger patients, in those with higher academic degree and in those who search information in sources different to that of health care professionals. Over half of patients (56.3%) perceived that the rheumatologist considered their opinion when prescribing an SC biological drug, a percentage higher in younger people. Only in 40.8% of cases did the patients' preference match their perception of their participation in the process. No differences were observed by sex, disease or number of biologics.

Conclusions: Patients with inflammatory rheumatic diseases want information about their treatments but mostly leave the prescription decision to the rheumatologist. Younger people, or those with higher academic degree, more often want to participate in the SDM. There are discrepancies between patient preferences and perceptions of this process.

Keywords: rheumatoid arthritis; shared decision making; spondyloarthritis; subcutaneous biological drugs; survey.

1 INTRODUCTION

Shared decision making (SDM) is defined as the process by which the patient and health care professional work together to make a therapeutic or diagnostic screening decision, using the best available evidence on the options while also respecting patient values and preferences (Elwyn et al., 2012). It therefore involves making an implicit decision to address the problem at hand, presenting options accompanied by comprehensible quantitative information; evaluating patient values, preferences and skills; checking correct comprehension; and explicitly taking or postponing the decision. There is growing interest in implicating patients in diagnostic and therapeutic decision making and in reaching owing to consensus between the patient and the health care professional (Chewning et al., 2012), in concordance with the ethical need to do so (Elwyn et al., 2012).

SDM is intimately related to what is known as ‘patient preferences’ (Brennan & Strombom, 1998). It is important to underscore that clinicians, patients, economists and health regulators often define preferences differently—a fact that has implications for study and research (Charles & Gafni, 2014). Preferences include assessments of all aspects or domains of health care, from treatment burden to health outcomes, life expectancy, method of administration or therapeutic regimen, referred to the treatment or the preferred professional for follow-up (Guyatt, Roman, Wilson, Montori, & Richardson, 2015; Muskett, 2014). In an SDM process, information should be provided tailored to the needs of the patient so that these preferences can be taken into account within an effective communication framework (Stacey et al., 2012).

The final choice of treatment may be adjusted to patient assessment of efficacy, adverse effects, administration route or dosage, among other parameters (Elwyn, Frosch, & Rollnick, 2009). The range of available subcutaneous (SC) biological drugs (with different efficacy and tolerability profile and different intervals of administration) makes selection of these therapies an opportunity to implement SDM processes between the patient and the health care professional. However, little is known of the degree to which SDM is implemented in our setting—characterized by limitations in consultation time—and of patient perceptions in this regard. The RHEU-LIFE study was designed to assess the perceptions of patients with rheumatic diseases (rheumatoid arthritis [RA], axial spondyloarthritis [axSpA], and psoriatic arthritis [PsA]) treated with SC biological drugs

on several aspects of their disease. In this work, we describe their preferences in terms of participation in SDM with the rheumatologist and how they perceived their participation when they were prescribed an SC biological drug.

2 METHODS

This is a subanalysis of the RHEU-LIFE study, designed to know the perception, impact upon quality of life and degree of satisfaction with treatment among patients with inflammatory rheumatic diseases treated with SC biological drugs (de Toro et al., 2017; Gonzalez et al., 2017). In the period between September to October 2015, the patients were invited to participate by physicians or nurses from rheumatology departments of 50 Spanish hospitals, which selected consecutive adults diagnosed with any of three target diseases (RA, axSpA and PsA) and treated with SC biological drugs from at least the medical visit prior to enrolment in the study and who, in the opinion of the rheumatologist, were able to understand and answer the survey. At each study site, the questionnaire was hand-delivered to 20 consecutive patients (total $n = 1,000$ patients) from among those meeting the inclusion criteria and who visited the outpatient clinic on a routine basis, regardless of age, gender, or the duration or severity of disease on the days on which the survey was open.

The patients received a sealed envelope containing the questionnaire and printed information on the purpose of the study and the voluntariness of answering all or part of the survey. The content of the survey made it impossible to identify the responders, thus ensuring anonymity. The patients agreeing to participate were instructed to answer the survey at home and return it in a prestamped envelope directly to the agency responsible for data tabulation and analysis. No reminders were sent, and no clinical data were collected from the case histories. The study and the contents of the survey were approved by the Clinical Research Ethics Committee of Hospital Gregorio Marañón (Madrid, Spain). According to the Committee, written patient consent was not required, and return of the completed questionnaire was taken to represent consent to participate.

2.1 Study questionnaire

The content of the survey was developed ad hoc for the RHEU-LIFE study with the participation of four rheumatologists experienced in the care of patients with rheumatic diseases and in the study methodology and was reviewed and completed with the suggestions of three patients from the ConArtritis patients association (Spanish National Osteoarthritis Coordinator), with the purpose of ensuring suitability of the questions and the language used. The survey finally comprised 54 closed-ended questions addressing the following aspects: socio-demographic characteristics, perceived impact of the disease upon daily life, aspects referred to how information was received about the disease and treatment, the prescription process of the SC biological drug, and logistic and follow-up issues. The results referred to perceived disease impact, preferences, satisfaction with treatment and information have been published elsewhere (de Toro et al., 2017; Gonzalez et al., 2017). A number of questions were designed to explore patient preferences and experience regarding SDM, which are presented here. Questions on SDM were designed as closed-ended questions with instructions for patients to select only one response. The list of questions and levels of response can be seen in the results tables.

2.2 Statistical analysis

The present survey was considered to be of an exploratory nature, and consequently, no hypothesis was made, and no formal sample size calculation was performed. Likewise, no imputation referred to missing values was made. Quantitative variables are reported as the mean and standard deviation (SD) and qualitative variables as percentages. Comparisons between percentages corresponding to different variables (age ranges, gender, background disease and others) were made using the chi-square test or the Fisher exact test. The categories 'very satisfied' and 'quite satisfied' were pooled into a single category to assess the degree of satisfaction, while the perceived degree of information was grouped into 'well/sufficiently informed' and 'little/not informed'. Statistical significance was considered for $p < 0.05$ in the different comparisons made.

3 RESULTS

3.1 Patient characteristics

Between September and October 2015, a total of 1,000 patients received the survey, and 592 returned it completed (response rate 59.2%). The mean age of the responders was 51.7 ± 13.2 years, and 42.4% were males and 57.6% females. The reported educational level was as follows: illiterate (8.3%), primary schooling (39.5%), secondary education (15.3%), professional (vocational) training (13.6%), and university or higher education (23.0%). As regards the SC biological drug, 60.4% of the surveyed patients reported being treated with a first SC biological drug, 26.1% with a second drug, and 13.5% with a third or successive biological agent. With regard to the information received about the SC biological drug, 45.3% of the respondents stated that they had received both verbal and written information, 6.1% had received only written information, 45.8% had received only verbal information, and 2.8% had received no information. In turn, 45.2% mentioned that they had sought additional treatment information outside the health professional circles (websites, general media or other people). Most of the patients (87.1%) considered themselves to be sufficiently or well informed about the SC biological treatment.

3.2 Patient preferences

Table 1 shows the patient preferences in relation to treatment decision making. Twenty-eight per cent of the responders stated that they preferred to take part in the choice of treatment, whereas the rest preferred to leave the decision to the rheumatologist. The percentage of responders who preferred to participate in the choice of treatment was higher among the younger and most educated subjects (Table 2). The percentage was also somewhat higher—without reaching statistical significance ($p = 0.160$)—among the patients prescribed with a first biological drug. The percentages were similar between men and women and also between the different disease groups (Table 2).

Regarding the information on the SC biological drug, there were no differences in preferences according to the way in which the patients received the information (verbal, written and both; $p = 0.344$, data not shown). However, the percentage who stated that they preferred to take part in the choice of treatment was higher among those who sought

information from sources other than the health care professional (37.8% vs. 20.1%; $p < 0.001$, Figure 1). Among those who considered themselves to be poorly or not informed, 20.0% stated that they did not request information and left the decision to their rheumatologist, as compared with 9.3% among those who considered themselves to be sufficiently or well informed ($p = 0.124$, Figure 1).

3.3 Patient perceptions

Table 3 reports patient perception of decision making when the biological drug was prescribed. A total of 56.3% of the patients considered that the rheumatologist had taken their opinion into account when prescribing the biological drug. The percentage was higher in younger patients ($p = 0.010$) (Figure 2) and similar between males and females ($p = 0.736$) and among the three disease groups ($p = 0.511$).

3.4 Relationship between patient preferences and perceptions

Table 4 shows the relationship between patient preferences and the perception of their intervention in decision making when the SC biological drug was prescribed. The percentage who considered themselves to have participated in the decision was greater among the patients who preferred to be informed and take part in decision making (64.8%), and smaller among those who did not request information and left the decision to the rheumatologist (37.7%) ($p = 0.001$). On excluding 25 patients who mentioned that they already had enough information and did not need any additional information, a total of 223 out of 547 patients (40.8%) described an involvement in decision of the SC biological, which was according with their declared preference, 239 (43.7%) described their involvement exceeding their preference, and 85 (15.5%) were falling short of their preference.

4 DISCUSSION

The present study describes the preferences of patients in SDM with the rheumatologist regarding the prescription of SC biological drugs, and their perceptions about how decision making was made in their case. Based on the answers obtained, it can be concluded that only slightly over one quarter of the patients preferred to play an active role in decision making, and discrepancy was observed in terms of patient preferences and perception of their participation in choosing the SC biological drug.

A little over one half of the patients, particularly the younger participants, considered that the physician had taken their opinion or preferences into account when prescribing the biological drug. This contrasts with the fact that less than 30% stated that they preferred to participate in the choice of treatment—thus raising doubts as to whether such perception is due to a systematic SDM process or not. No questions or questionnaires were included in the study to explore this aspect in depth. Accordingly, we can only describe patient perception, without being able to certify the existence of an SDM process as such. However, it is interesting to note that in most cases the patients appeared to be given the opportunity to express their opinion or at least their agreement with the rheumatologist despite the limited consultation time.

There is increasing evidence that decision making aids can improve choices in a manner consistent with the patient situation and values, without counterproductive effects upon health outcomes or satisfaction. It has been reported that patients who participate in SDM with their physicians show greater improvement in the affective and cognitive domains, greater satisfaction and fewer conflicts in making decisions and are responsible for their care and adherent to the chosen treatment option (Shay & Lafata, 2015). Therefore, SDM must be implemented as a further quality standard to be considered in daily clinical practice (Gossec et al., 2016; Ravelli et al., 2018; Smolen et al., 2010, 2017). However, information and training on how to bring this into effect are limited. SDM could be implemented progressively, initially selecting the patient profiles most favourable to it. Based on the findings of our survey, such profiles would include the younger subjects, those with the highest educational level and those with an interest in knowing their disease and its treatments—these being the individuals with the greatest preference for participating in the choice of their SC biological treatment.

In relation to information, the great majority of respondents claimed to be well or sufficiently well informed about the characteristics of the treatment. However, almost half of them had sought additional information from sources outside the health care professional circles. Nevertheless, a recent study has reported that only 13% of all patients with rheumatic diseases claim to have been oriented by health care professionals about where to seek reliable information on the Internet (Orozco-Beltrán et al., 2019). It therefore may be pertinent to guide patients requiring information towards reliable and up-to-date data sources in order to improve their knowledge of the disease. In this regard, the websites of patient associations or patient sections of scientific societies may be a good source for helping patients to better understand their illness.

A fundamental aspect in SDM is patient training in the understanding of probabilities and risks, and visual aids facilitate the transmission of such information (Garcia-Retamero & Cokely, 2013). These decision-making aids appear to reduce the proportion of indecisive participants and have a positive effect upon physician–patient communication (Legare et al., 2018; Shepherd et al., 2016; Stacey et al., 2012, 2017). A Cochrane review found that the use of SDM aids during or in preparation of consultation favours better understanding and clear perception of risk on the part of patients (Stacey et al., 2017). Furthermore, individuals offered a decision-making aid tool are equally or more satisfied with their decision, the decision-making process and/or preparation for decision making compared with standard care (Stacey et al., 2017). Although a willingness on the part of rheumatologists to inform their patients when making treatment decisions is observed, the incorporation of information about patient choices and preferences is not fully reflected in the patient perceptions of the SDM process. The development of specific tools for rheumatology in support of the SDM process between health care professionals and patients could cause patients to become more involved in the management of their disease.

The limitations of our study include its design in the form of an anonymous survey, which does not allow us to know whether the characteristics of nonresponders were similar to the responders, and the fact that only patients subjected to biological (and specifically SC) treatment were included. Although the patients were selected on a consecutive basis, we cannot discard bias among the participants who returned the survey, as these could have been patients with greater motivation in relation to health care. Given the

characteristics of the study, no disease activity data or other parameters were collected from the case histories. As a result, it cannot be determined whether SDM may be related to disease activity or to other clinical parameters. The main advantage of an anonymous survey format like the present is that reduce response bias, because the patient is not observed by the investigator.

In conclusion, patients with inflammatory rheumatic diseases wish to participate in decision making, at least being informed on the different therapeutic options, although most of them prefer to leave the decision in the hands of the rheumatologist. Younger or more highly educated patients are those who most often want to actively participate in decision making. One half of the patients felt that they had participated to some extent in this process, though discrepancy was observed between patient preference and patient perception of participation in the process. Further training to health care professionals and patients in making shared decisions and useful tools are needed so that more patients can receive the information they require and actively participate in the decision-making process.

ACKNOWLEDGEMENTS

This project was funded by MSD Spain and was reviewed and endorsed by the ConArtritis patients association (Spanish National Osteoarthritis Coordinator). Data analysis was performed by Alejandro Pedromingo (www.bio-estadistica.com). Thanks are due to the health care professionals who contributed to implement the survey and particularly to the patients for completing and returning the questionnaires.

CONFLICT OF INTEREST

Luis Cea-Calvo, María J. Arteaga and Sabela Fernández are full-time employees of MSD Spain. The rest of the authors received fees as consultants for the present study. Carlos M. González has received speaker fees from MSD. The rest of the authors declare that they have no conflicts of interest.

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TABLE 1. Answers to the question: ‘To what extent do you prefer to take part in choosing the treatment for your illness?’

Answer	n (%)
I prefer to have information on the different options for treating my illness and to take part in choosing the treatment.	165 (28.2)
I like to have information on the different options for treating my illness but leave the treatment decision to the rheumatologist.	357 (60.9)
I ask for no information on the different treatments; I simply leave all the decisions to the rheumatologist.	64 (10.9)

Note: Six patients did not answer this question.

TABLE 2. Patient preferences according to different profiles

		Information and decision (%)	Information, no decision (%)	No information, no decision (%)	<i>p</i>
Age (quartiles)	Q1 (18–42)	38.7	53.5	7.7	<0.001
	Q2 (43–52)	33.8	57.0	9.2	
	Q3 (53–61)	25.2	65.2	9.6	
	Q4 (62–91)	14.6	68.5	16.9	
Gender	Male	29.8	60.0	10.2	0.390
	Female	26.5	62.3	11.1	
Educational level	Illiterate	12.2	59.2	28.6	<0.001
	Primary	15.7	71.6	12.7	
	Secondary	36.4	53.4	10.2	
	Professional	30.0	63.7	6.3	
	University	47.0	48.5	4.5	
Biological drug	First	31.1	57.8	11.1	0.160
	Second	25.7	66.4	7.9	
	Third or successive	21.5	65.8	12.7	
Background disease	Rheumatoid arthritis	26.1	64.9	9.0	0.670
	Axial spondyloarthritis	31.9	58.2	9.9	
	Psoriatic arthritis	31.3	53.9	14.8	

Note: The three columns correspond to the three groups defined by the answers to the question displayed in Table 1: (1) information and decision, ‘I prefer to have information on the different options for treating my illness and to take part in choosing the treatment’; (2) information, no decision: ‘I like to have information on the different options for treating my illness but leave the treatment decision to the rheumatologist’; (3) no information, no decision, ‘I ask for no information on the different treatments; I simply leave all the decisions to the rheumatologist’. Q, quartile.

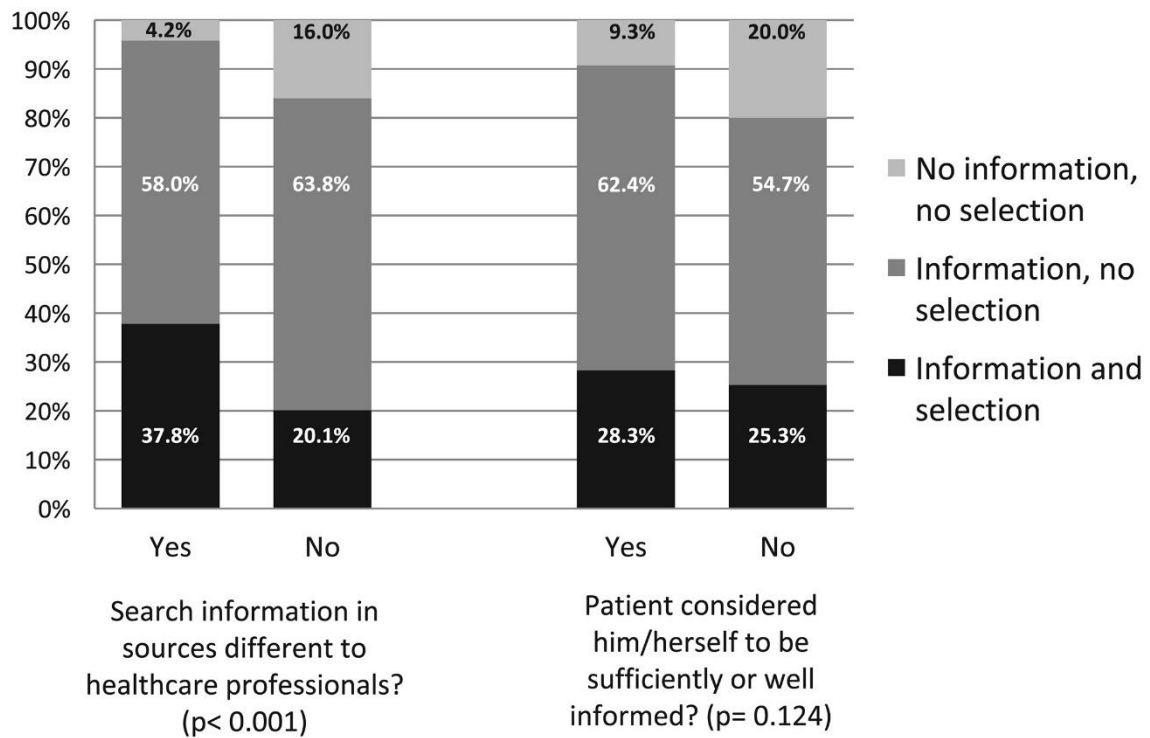


FIGURE 1. Patient preferences and aspects related to drug information. The three groups correspond to the following answers: (1) information and decision, ‘I prefer to have information on the different options for treating my illness and to take part in choosing the treatment’; (2) information, no decision, ‘I like to have information on the different options for treating my illness but leave the treatment decision to the rheumatologist’; (3) no information, no decision, ‘ask for no information on the different treatments; I simply leave all the decisions to the rheumatologist’

TABLE 3. Answers to the question: ‘How was the subcutaneous biological drug prescribed in your case?’

Answer	n (%)
They explained me several options, and the doctor took my opinion and preferences into account in choosing the subcutaneous biological treatment.	324 (56.3)
They explained that there were several options available, but the doctor made the decision without asking my opinion or preference.	167 (29.0)
They prescribed the drug but did not explain the different options available, and I was not asked about my opinion or preferences.	60 (10.4)
I already had enough information and did not need any further information.	25 (4.3)

Note: Sixteen patients did not answer this question.

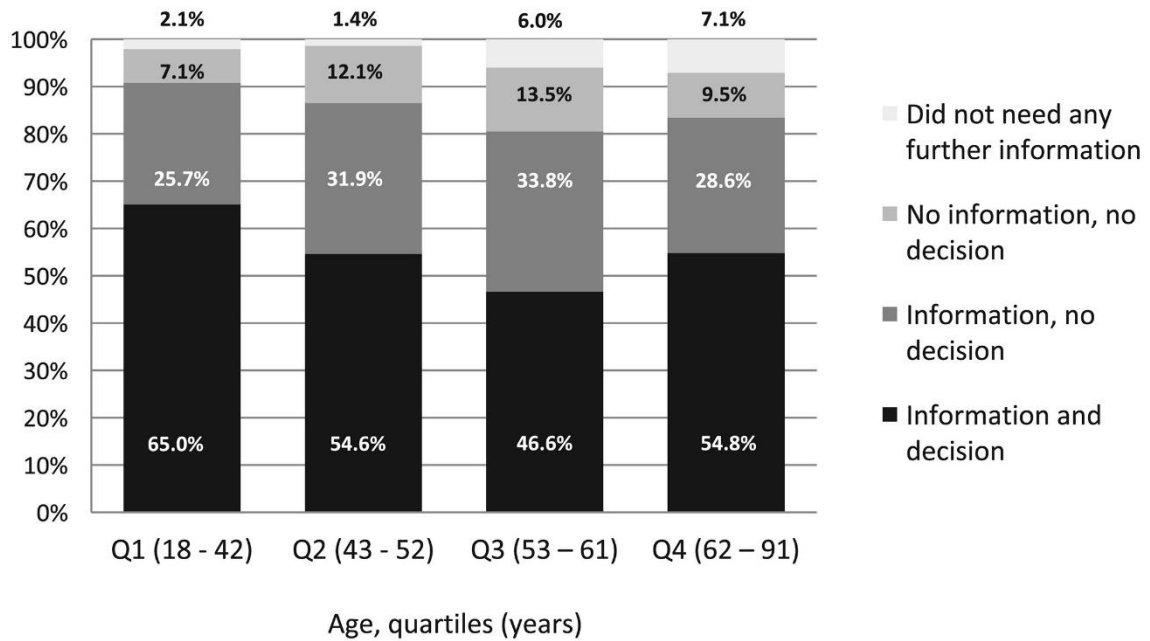


FIGURE 2. Patient perception of participation in decision making when prescribing the subcutaneous biological drug by age ranges ($p = 0.010$). The four groups correspond to the following answers: (1) information and decision, ‘They explained to me several options, and the doctor took my opinion and preferences into account in choosing the subcutaneous biological treatment’; (2) information, no decision, ‘They explained that there were several options available, but the doctor made the decision without asking my opinion or preference’; (3) no information, no decision, ‘They prescribed the drug but did not explain the different options available, and I was not asked about my opinion or preferences’; (4) did not need any further information, ‘I already had enough information and did not need any further information’

TABLE 4. Patient preference and perception of participation in the decision to prescribe the biological drug

		Patient preference		
		Information and decision (%)	Information, no decision (%)	No information, no decision (%)
Patient perception	Information and decision	105 (64.8)	194 (55.6)	23 (37.7)
	Information, no decision	34 (21.0)	110 (31.5)	22 (36.1)
	No information, no decision	19 (11.7)	32 (9.2)	8 (13.1)
	Already had enough information	4 (2.5)	13 (3.7)	8 (13.1)

Note: The three groups correspond to the following answers: (A) PREFERENCES: (1) information and decision, ‘I prefer to have information on the different options for treating my illness and to take part in choosing the treatment’; (2) information, no decision, ‘I like to have information on the different options for treating my illness but leave the treatment decision to the rheumatologist’; (3) no information, no decision, ‘I ask for no information on the different treatments; I simply leave all the decisions to the rheumatologist’. (B) PERCEPTION: (1) information and decision, ‘They explained me several options, and the doctor took my opinion and preferences into account in choosing the subcutaneous biological treatment’; (2) information, no decision, ‘They explained that there were several options available, but the doctor made the decision without asking my opinion or preference’; (3) no information, no decision, ‘They prescribed the drug but did not explain the different options available, and I was not asked about my opinion or preferences’; (4) already had enough information, ‘I already had enough information and did not need any further information’. Data are shown as *n* (%). The difference between groups is statistically significant ($p = 0.001$).