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THE BURDEN OF RHEUMATIC DISORDERS WITHIN A LOCALITY

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Introduction: Rheumatic Disorders (RD) are the more frequent causes of morbidity and long – term disability in the population; they are a major problem of the public health all over the world.
Objectives: Description of the consequences of Rheumatoid Arthritis (RA), the most common Chronic Inflammatory Arthropathy in the patients of Gjirokaster Region. Showing the quality of the health care offered to patients at a local level, comparing it to the standards and needs of this particular population of the community.
Patients and methods: In the descriptive study, we included the RA diagnosed patients during the period 1995-2011, who were registered at the Rheumatology Service of the Regional Hospital of Gjirokaster, diagnosed on the basis of the relevant criteria.
Results: Out of 110 individuals diagnosed with RA, (88 females): 4.5% have died, 5.4% have lost the ability to take care for themselves, 34. 5% have lost the ability to perform professional, nonprofessional activities. All the patients afforded a considerable portion of direct costs for diagnostics, monitoring, medication. The region has lacked non-pharmacological treatment: rehabilitation, physical therapy, education.
Conclusions: The burden of Rheumatic Disorders is large; highlighting this significant responsibility can be a means in finding resources for improving the standards of care on local level to prevent the consequences (death, disability), to improve the survival and life quality of patients in our Region. It can place the RD in the perspective of healthcare policies and reimbursement decision-making, as well as of public health preventive policies.
Key words: Cost, disability, Rheumatoid Arthritis, Rheumatic Disorders.

Introduction

Rheumatic Disorders (RD) are the more frequent causes of morbidity and long – term disability in the population [1], they are a major problem of the public health all over the world [2]. They include arthropathies, connective tissue disorders, back disorders, soft tissue rheumatism and bone disorders [1]. These disorders are chronic in nature, often relapsing and remitting in unpredictable ways [3,4], sometimes shorten life expectancy and almost always result in disability [5]. The prevalence of disability caused by the RD is approximately 5-10% of the population; it is estimated that 0.5% are disabled to such an extent that they need daily assistance with everyday living activities. Mortality from them is low, the annual death rate being less than 0.02% [1]. The course of these disorders can be influenced by many factors, including biological processes, family and societal interactions, education, and treatment [6]. Who is consulted will depend not only on the nature of the condition, but also on the local aspects of healthcare delivery [1]. As well as significant human impact, RD-s also make a huge economic impact [1,7] on national economy and individual microeconomics [8]. They have direct costs to the health and social care for ensuring care in the community, including diagnosis, treatment, and rehabilitation of patients in province. These costs reflect the rules of reimbursement for the care about people with RD [8]. They have direct costs to individuals, related with any changes in the living status, changes that are necessary to adopt and make domestic environment more functional [8]. To individuals and family members, they also have indirect costs, as a result of the disease, including the loss of the workplace and the early retirement [8]. Loss of function, increased pain, reduced quality of patient's life, make up the intangible costs [8]. RD chronic condition means that these disorders bring about consequences to individuals, families and the community [1].

Objectives

The study aims at providing data on the occurrence of most common Chronic Inflammatory RD-s, the Rheumatoid Arthritis (RA) in the period 1995-2011 in the Region of Gjirokastra. It describes the consequences of the disease in the individuals diagnosed during this period. It shows the quality of the health care offered to patients on a local level by comparing it with the standards and the needs of this particular population of the community [1]. This coverage will raise awareness about the RD burden on individuals, their families and about their responsibilities in the community.

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Patients and methods

In order to show the RD responsibility in the region, we selected the patients with the most common Chronic Inflammatory Arthropathy, Rheumatoid Arthritis (RA). In our selection, we took into consideration the fact that this disease affects all ethnic groups and presents a reasonable frequency among the population, 1% - 2%. It is also a clinical reality defined by strict criteria, within the clinical, radiological and serological context [1]. The diagnosing of our patients has been made on the bases of the criteria of the American Rheumatology Association (ARA) in 1987 [9] thus meeting also the criteria approved recently by the American College of Rheumatology / European League Against Rheumatism (ACR/EULAR) 2010 [10]. Also 75.3% of our diagnoses (No.83) are confirmed at the Rheumatology Clinic, QSU Tirana, and 24.5% (No.27) at the rheumatology clinics abroad (Greece), (the geographical position favors the consultations of the patients of the region at these clinics).

Results

Table nr.1. General details of patients

Details	Characteristics	Comments	Values
		Total: No.	110
General		Females No. (%)	88 (80)
	Average start age (years), (SD)		45.2 (12.6)
	Delay in diagnosing (years), (SD)		3.1 (3.4)
	Present average age (years), (SD)		54.9 (12.4)
		≤40 years No. (%)	14 (12.7)
		40 - 60 years	53 (48.1))
		≥60 years	38 (34.5)
Mortality			5 (4.5)
	RAAverage Duration (years), (SD)		9.5 (6.2)
		≤ 10 years No. (%)	57 (51.8)
		11 – 17 years	42 (38.1)
		>17 years	11 (10.0)
Present functional status		ACR 1991	
	Class I		23 (21.9)
	Class II		38 (36.1)
	Class III		38 (36.1)
	Class IV		6 (5.7)
Used medicatio ns			
	NSAIDs No. (%)		110 (100)
		Regularly	68 (61.8)
		Acc. to needs	42 (38.18)
	GCs		
		Regularly No. (%)	100 (90.9)
	DMARDs No. (%)		105 (95.4)
	Synthetic No. (%)		87 (79%)
		Methotrexate, No. (%)	75 (86.2)
		Plaquenil No. (%)	4 (3.8)
		Sulfasalazine, No. (%)	8 (7.2)
	Biological Nr (%)		18 (16.3)
		Leflunomide	12 (10.9)
		Infliximab	1 (0.9)
		Adalimumab	1 (0.9)
		Anakinra	1 (0.9)
		Golimumab	1 (0.9)
		Rituximab	1 (0.9)
		Abatacept	1 (0.9)

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SD, Standard Deviation; ACR, American College of Rheumatology; Class I, able to perform usual activities of daily living; Class 2, able to perform usual self care and vocational activities, but limited in avocational activities; Class III, able to perform usual self-care activities, but limited in vocational and avocational activities; Class IV, limited in ability to perform usual self-care activities, vocational and avocational activities; NSAID, Non-Steroidal Anti Inflammatory Drugs; GCs, Glucocorticoids; DMARD, Disease- Modifying Anti-rheumatic Drug;

Table nr.2. Demographic data of patients

Characteristics	Comments	Values No. /%
		110 (100)
Residence	Gjirokastër	48 (43.6)
	City	25 (52)
	Tepelenë	34 (30.9)
	City	12 (35,2)
	Permet	28 (25.4)
	City	13 (46.4)
Education	≤ 8 years	61 (55.4)
	≤ 12 years	41 (37.2)
	≥ 12 years	8 (7.2)
Occupation	Worker	72 (65.4)
	Farmer	30 (27.2)
	Employee	8 (7.2)

Discussions

The management of patients with RD is complex due to the chronic nature of these disorders, the need for continuous monitoring of the activity of the disease and their medication, the need for a multidisciplinary therapeutic approach [6,8].The medical subspecialty most concerned with these disorders is rheumatology [1]. In the Gjirokastra Region, rheumatologic service is provided by the Regional Hospital. Traditional rheumatologic care is offered in the office–based practice of rheumatologists, with their practice in full service to inpatient and outpatient units: 2 rheumatologist for a population of 112.831 inhabitants (30.150 inhabitants at the ages 0-14 years, 72.172 at the age 15 - 65 years and 10.499 inhabitants over 65 years old) [12]. During the period 1995 – 2011, 110 individuals with RA (88 females, 80%) were registered in the Rheumatology Service. The average age of the onset of the disease was 45.2 years (SD 12.6). The current average age of patients was 54.9 years (SD 4.12), Mortality was 5 patients (4.5%), RA average duration was 9.5 years (SD 6.2). The average delay in the determination of the diagnosis was 3.1 years (SD 3.4).

The current functional status of the patients according to the classification of the American College of Rheumatology (ACR) 1991 [13] was: 6 patients (5.4%) with limited abilities to perform self-care and professional and nonprofessional activity (class IV) [13], 38 patients (34.5%) were able to perform the usual self-care activities, but limited in professional and nonprofessional activities, (class III) [13]. 23 patients (20.9%), presented joint injuries [14] and 38 patients (34.5%), presented functional limitations [14], but retained ability to perform actions or activities within the limits considered normal [14], (classes I and II ACR 1991) [13]. During the years of the study, 5 patients died (4.5%), who had been assessed within disability groups III or IV. In our group of study (110 patients), 42 patients (38.1%) had benefited early retirement. 19 patients (45.2%) of this group had been co-living with the disease for 1-10 years and 23 patients (54.7%) had been co-living with the disease for 10 - 20 years. RD-s are a major cause of lost work capacity and premature retirement, they lead to enormous yet inevitable disability and costs to society [7].

RD-s is often life -long, unstable and necessitate constant monitoring of their activity, therapies, of the functional status [1, 5]. Their requirements can be totally hospital - based [1]. Physicians treating these disorders within a locality, need supporting services, such as laboratory services and X-rays. Laboratory services are required not only for the diagnosis, but also for the monitoring of treatment [1]. In Gjirokastra Hospital, laboratory service suffers shortages in the realization of serological tests required for classification and the acute stage indicators [9,10]. The direct costs of these examinations have been afforded by our patients.

RD's are characterized by episodes of disease exacerbation which may have significant sequelae unless the correct line in management is taken [1]. Drug treatment includes Disease-modifying Anti-rheumatic Drugs (DMARDs), Non-steroidal anti-inflammatory drugs (NSAIDs) and the glucocorticoids (GCs) [15]. The mainstay of treatment is the application of DMARDs, which has undergone dramatic changes during the past decade, providing previously unforeseen therapeutic dimensions. Methotrexate (MTX) is a highly effective drug for disease modification in RA [15] and in the region of Gjirokatser, 79% of patients are treated with synthetic DMARD and 86.2% of them with MTX. The adding of a biologic DMARD

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should be considered when poor prognostic factors are present [15] and 16.3% of our patients are treated with biological DMARDs. Glucocorticoids (GC) have been shown to have not only anti-inflammatory, but clearly also disease modifying-properties [15], 90.9% of the patients are regularly treated with low GC doses. Our patients have been affording the direct costs of medications with synthetic and biological DMARD themselves, as these preparations are not included in the scheme of reimbursable drugs for the treatment of RD patients. Table 1 and Table 2 provide more detailed information about the medical history of the patients and their demographic data.

While medical management will be an important component of the care, for many condition it will be just one component of a necessary wide package [1]. Major therapeutic strategies include not only pharmacotherapy, but also non pharmacological measures (rehabilitation, education, physical therapy) [6], together, they can lead to therapeutic success [15]. The modalities ensuring non medical management of disorder in the region have been missing for our patients.

We made this description of the RA consequences in the patients of the Region, of the level of the care provided to them as compared with the standards and their needs, in order to raise the awareness about the quality of the patients' life. The quality of life, according to the WHO definition of health, is a state of complete physical, mental, and social well – being, but not merely the absence of the disease or infirmity. Quality of life is affected by each stage of the disability process [14]. We found the quality of the life of the patients of the group we studied in the chronic disease, in the long term disability and in premature retirement, in the patients' affording the direct costs for diagnosing and treatment, in the lack of non pharmacological treatments. The overall economic impact of the disease on the individual is assessed by the use of health care and the social care resources, as well as by disability to work [8]. "Chronic Arthritis often enmeshes inextricably with the patient's life over a decade, a quarter of century, or even more. It can span crucial periods of life; it may be particularly disruptive to the individual emerging into adult life" [16].

The study reflected realistically the consequences in patients with RA, the most common RD, diagnosed during the period 1995-2011 in the Region of Gjirokastra. Our aim was to show what the disease has caused to the patients during the years of their cohabitation. The burden of RD in community comes from general survey of the population [1]. The study has not included the patients with RA diagnosed before the years of the study (45 patients), who were also registered at our clinic. The geographical position (a border region with Greece), emigration and immigration, the weak functioning of the referral system of the patients during the years of study, the level of civic education in seeking medical assistance, make us believe that not all the persons with the disease involved in the study (RA) have consulted a specialist physician in the Region. This study did not include patients with other chronic inflammatory arthropathies living in our region: Ankylosing Spondylitis (No.49), Psoriatic Arthritis (No.18), Juvenile Idiopathic Arthritis (No. 30), etc. We think the number of patients we studied (110) was enough to highlight the fact that it is necessary to react against RD consequences on individuals, families and communities.

Conclusion

The burden of Rheumatic Disorders is large; highlighting this significant responsibility can be a means in finding resources for improving the standards of the care on local level to prevent the consequences (death, disability), to improve survival and life quality of individuals, their families, the society in the Region of Gjirokastra. It may help in the placing of the Rheumatic Disorders in the perspective of healthcare policies and reimbursement decision-making, as well as of preventive public health policies.

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