

Integrated care process for systemic lupus erythematosus: towards quality in healthcare

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Dear Editor,

The concept of integrated care has raised a lot of interest in recent years, as a patient-centred approach valuing coordination and continuity of care¹. Integration can be defined as the process of bringing organizations and professionals together to improve outcomes for patients². Integrated care processes (ICP) imply the articulation of medical and nursing professionals, hospital departments, primary healthcare, and long-term integrated care. Disease management programs usually focus on patient education, multidisciplinary care, provider education, use of evidence-based guidelines, and quality assurance measures³. ICPs for patients with chronic diseases are associated with improvements in processes and outcomes of care, patient satisfaction, therapeutic adherence, disease control and health costs⁴. Systemic lupus erythematosus (SLE) is a chronic systemic rheumatic immune mediated disease that requires a regular systematic follow-up and multidisciplinary approach⁵.

We aimed to describe the development of an ICP for SLE patients and the evaluation of its indicators in our Lupus clinic cohort.

The development of the ICP started with the definition of the profile of patients eligible to be enrolled in this process and the health professionals involved. Specific activities and competencies were defined for each professional. The resources and support units were identified. Considering the different parts of the process, an information roadmap was developed (Figure 1). To evaluate and monitor the implementation results of the ICP, a set of quality indicators and specific endpoints was defined for the patients followed at the SLE

clinic of Rheumatology Department, Centro Hospitalar Universitário Lisboa Norte. The indicators were analysed before and after ICP implementation.

The ICP for SLE was designed for patients with a high suspicion or confirmed SLE, and in order to be maintained in the pathway, patients should fulfil American College of Rheumatology 1997⁶ or Systemic Lupus International Collaboration Clinics 2012 classification criteria⁷. Patients can be referred from external centres such as the primary care units or other hospitals or from our centre. Exit criteria are exclusion of a SLE diagnosis, patients' expressed will of interrupting the follow-up at the clinic, drop-out, or death. This ICP includes all the units of our department, comprising doctors with specific training in SLE, nurses, administrative staff, a specialized psychologist and nutritionist. Other departments, namely Ophthalmology and Dermatology are consulted whenever necessary. The quality standards defined for the professional's activities were based on international guidelines and good practices in the management of SLE patients. The procedures for the first appointment and follow-up visits were outlined. There is a special emphasis on communication and information to the patient about the disease, therapeutic options and her/his active role in the decision process. The quality indicators defined to monitor the ICP focus on patient's satisfaction, complications of the disease and therapeutics, management of comorbidities, quality of records, and socioeconomic impact. Implementing the ICP resulted from the reorganization of existing resources with no additional costs for the hospital or patients. In the year before ICP implementation, we followed 277 patients at the SLE clinic, 92% female, with a mean age of 49.0 ± 14.6 years. Two-years after this evaluation 135 new patients had been included in this pathway and we now analysed the indicators for the 412 patients followed (92% female, with a mean age of 49.8 ± 14.4 years). The SLE ICP indicators and their evaluation are described in

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TABLE I. INDICATORS TO MONITOR THE SLE ICP – OBJECTIVES AND RESULTS IN THE BASELINE EVALUATION AND AFTER 2 YEARS

Indicator	Objective	Baseline evaluation (n= 277)	2-year evaluation (n=412)
Patient complaints	Gradual decrease	0 (0%)	0 (0%)
Registration in reuma.pt	100% (>60% appointments)	145 (53%)	226 (55%)
Ratio of hospitalization from scheduled appointment/emergency department	Gradual increase	4/5	3/8
Complications from systemic glucocorticoid therapy (diabetes, secondary osteoporosis, aseptic necrosis)	Gradual decrease	34 (12%)	61 (15%)
Irreversible visual loss related to antimalarials toxicity	0%	3 (1%)	3 (1%)
Cardiovascular events	Gradual decrease	2 (1%)	3 (1%)
Outcomes in lupus nephritis: end stage renal disease or submitted to transplant	Gradual decrease	6 (2%)	11 (3%)
Miscarriages	Gradual decrease	1 (in 4 pregnancies)	1 (in 8 pregnancies)
Term pregnancies	Gradual increase	2 (in 4 pregnancies)	6 (in 8 pregnancies)
Temporary incapacity for work decided by the rheumatologist	Gradual decrease	1 (0.4%)	4 (0.9%)
Requests for medical reports for evaluation of incapacity	Gradual decrease	16 (6%)	30 (7%)

ICP - Integrated care processes; Reuma.pt: Rheumatic Diseases Portuguese Register; SLE - Systemic lupus erythematosus

Table I. Two-years after ICP implementation, the objectives for 6/11 indicators were accomplished. Referring to a tertiary centre increases the patient's complexity, leading to slight worsening of the performance of indicators reflecting irreversible conditions.

ICPs are considered one of the essential characteristics of high-performing chronic care systems⁸. Besides the health professional's role, patients are expected to play an active role based on shared decision-making. Integrated care of patients at a specialized reference centre is only possible with a multidisciplinary team, with adequate resources.

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