Health information technologies in systemic lupus erythematosus: focus on patient assessment

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ABSTRACT

Recent advances in health information technologies (HIT) in systemic lupus erythematosus have included electronic databases and registries, computerised clinical charts for patient monitoring, computerised diagnostic tools, computerised prediction rules and, more recently, disease-specific applications for mobile devices for physicians, health care professionals, and patients. Traditionally, HIT development has been oriented primarily to physicians and public administrators. However, more recent development of patient-centered Apps could improve communication and empower patients in the daily management of their disease. Economic advantages could also result from the use of HIT, including these Apps by collecting real life data that could be used in both economic analyses and to improve patient care.

Introduction

In recent years, Health Information Technology (HIT) has gained substantial importance for diagnostic, therapeutic and prognostic purposes as well as disease management in different fields of medicine and in rheumatic diseases, including in the management of systemic lupus erythematosus (SLE) patients (1-8). Major applications of HIT in SLE include electronic databases and registries, computerised clinical charts for disease monitoring, computerised diagnostic tools, computerised prediction rules and, more recently, disease-specific applications for mobile devices (9-11). Physicians, patients, and public administrators are the users of these data.

In this review we summarise the applications of HIT for the assessment and management of patients with SLE. Available instruments to guide the treating physician in diagnosis, prognosis and assessment of disease activity and damage are reviewed.

Health information technologies in SLE: why?

The increasing number of transitions of patients between institutions and care services puts high demands on the quality of the communication of medical information among different health care settings, especially for patients with chronic diseases, multiple comorbidities and concomitant therapies such as SLE patients. Continuity of care, which is crucial for high quality patient care, requires close cooperation between healthcare professionals and patients.

Indeed, the management of patients with SLE remains a clinical challenge. The clinical picture is characterised by extensive variation among patients, as well as in the same patient over time. This variation is explained by many features of SLE, including the protean clinical manifestations of the disease, fluctuation between remission and exacerbation over time, coexistence of manifestations related to irreversible damage, occurrence of comorbidities, and treatment side effects.

Some results

In SLE, the first attempt to gather clinical information to guide the physician in the differential diagnosis reasoning probably dates back to 1973, when Fisher *et al.* presented a computerised programme aimed at helping the treating physicians in a rapid differential diagnosis between the most common causes of fever accompanied by skin rash (12).

Thereafter, many efforts have been focused on patient monitoring.

One study documented gains in efficiency of rheumatology consultation through an electronic referral system (13). Another study identified predictors of transaminase elevations in an incident-user cohort of patients with rheumatic diseases (including SLE) receiving methotrexate, in using data derived from an electronic health record (14).

The American College of Rheumatology is promoting an initiative aimed at developing a core set of electronic clinical quality measures (eCQMs) as a new approach to quality of care measurement that automatically extracts information from electronic medical records, potentially allowing a rapid feed-back on performance data for quality improvement (15, 16).

What data to assess SLE?

The importance of the extensive use of HIT is crucial in SLE because of the complexity of the disease and the variability in the clinical judgment among physicians (17). It is widely accepted that assessment of patients with SLE should take into account disease activity, organ damage, drug toxicities and patient's quality of life. Disease-specific indices have been developed to assist the physician in the clinical assessment of SLE patients in clinical trials as well as in routine clinical practice. One single index to assess irreversible organ damage is available, the SLICC damage index (18). Further, patient driven-instruments to evaluate disease activity and damage have been also proposed (18).

The reproducibility, validity, responsiveness and the sensitivity to change of these instruments have been demonstrated, and these indices are largely used in clinical trials and in clinical research. The use of disease activity indices in routine clinical practice is recommended but might be difficult.

One alternative could be to use the RAPID3 (routine assessment of patient index data) score, which has been found to be correlated significantly with traditional SLE indices (19). It appears informative in many rheumatic diseases, with all work completed by the patient in 5 minutes or less (20).

HIT in SLE

The complexity of SLE and unsatisfactory experience in attempting to use quantitative data beyond laboratory tests in routine clinical care, suggest an approach to gather clinical information into computerised systems with capacity to rapidly summarise data in a comprehensive and user-friendly manner.

Table I. The most diffuse Apps dedicated to the management of SLE.

App	Costs (€)	Developer
The Lupus App	2.99	Shashank Akerkar
We Can Beat Lupus	free	We Can Beat Lupus
My Lupus Log	free	Glaxo Smith Kline
LupusTracker Pro	2.17	ToTheHand, LLC
Cure Lupus	free	Phenomaps
Lupus Companion	free	American College of Rheumatology
Lupus Connect (community)	free	Alliance Health Network
MyLupusTeam (social network)	free	MyHealthTeams
Lupus Diary	4.99	HomeInSync LLC
Lupus Signs And Symptoms	2.99	Gary O'Brien
Nutrition Lupus	free	Doctor World Ltd.
Loving U Pass Your Sickness	free	Mobile Media Solutions LLT
Lupus Disease	free	SumedangSakti

The first attempt in this direction was a European Consensus Group initiative based on the European Consensus Lupus Activity Measurement (ECLAM) index. A standardised clinical chart (ACTICARD) was developed, together with a computer programme that could automatically calculate the ECLAM score, as well as the British Isles Lupus Assessment Group (BILAG), Systemic Lupus Activity Measure, SLE Disease Activity Index, and the SLE Index Score (SIS). The goal of this project was to offer a simple and reliable instrument to assess disease activity that could be used to monitor lupus patients both in clinical practice and in clinical trials (21, 22). However, despite these preconditions, the feasibility of ACTICARD is still perfectible and this is the reason why up to now the project is not widely implemented in different clinical settings.

Another attempt was the BLIPS 8™ software programme, developed by ADS-Limathon in collaboration with the BILAG Group. The first version, the BLIPS™, was a simple application for clinicians and researchers to acquire patient health and laboratory data and monitor response to drug treatments. In 2005 the i-BLIPS™ was released as an internet-based, hosted service (23). Subsequently, updated versions have been released to guarantee a larger browser compatibility. Demographic, clinical and laboratory information can be entered and scores on disease activity, organ damage and patient's quality are easily calculated; moreover, simple data description can be performed and data can be easily exported into statis-

tical analysis software (24). This programme is widely adopted in clinical trials and in national lupus registries, but it can be also available for single clinic research.

Unmet needs and future perspectives

SLE has a major impact on a patient's quality of life, which is influenced not only by clinical manifestations, but also by the psychosocial aspects of the disease. Moreover, In SLE there may be discordance between the patient's and physician's view of the disease, leading to possible difficulties in coping with the disease as well as in disease management and adherence to therapy. Moreover, some problems experienced by patients, such as fatigue, pain, and functional disability, are much more accurately described by patients than by doctors. These problems contribute significantly to the disease burden, but are not captured by the traditional indices, which are mainly based on measures made by the physician (18).

There is a growing evidence that disease activity and/or organ damage are not strongly associated with measures of quality of life, suggesting that these measures assess different aspects of the patient status (25). One reason for this unclear situation might be attributed to discrepancies between patient and physician assessments of the disease. Discordance between patients and physicians carries clinical significance: it can negatively affect patient care, adherence to treatment, and outcomes of the disease.

Recent implementation of health Apps for smartphones present a potential tool

to increase patient empowerment in the disease management and reduce communication gaps. The market for health Apps, in fact, is exploding worldwide and is characterised by development of Apps designed for public education, to serve as health diaries and to support health practitioners. Approximately, 70% of them are Apps planned for customer uses in the field of wellness and fitness, and the remaining 30% Apps are for healthcare professionals, patient consultation and monitoring, access to patient data, diagnostic, pharmaceutical (26).

Several Apps are available for patients with SLE; most of them are patient-oriented, suggesting the existence of an unmet need to monitor different aspects of the disease from a patient's perspective (Table I).

These Apps have been reviewed by patients and patient groups, the following aspects were considered to rate existing health Apps to empower patients: 1) how the App will help the patient to control his/her conditions, 2) trustworthiness, 3) networking with other patients, 4) easy to use, 5) regularity of use. The selected ten Apps have received a very poor score in the regularity of use (myhealthapps.net).

Apps could also be useful to collect data concerning issues relevant to economic effects of SLE. It is well known that SLE is associated with a high economic burden; however, few studies are available on this aspect with significant limitations which results from methodological issues and limits inherent the specific disease (*i.e.* low prevalence, variability of manifestations, and fluctuation between remission and exacerbation) (27).

In view of the development of novel therapies, the appropriate collection of data could allow consistent assessment of the economic effects, which may be useful for the health economic evaluation of innovative therapies, as well as the assessment of novel therapeutics pathways.

In summary, such an ideal system, while improving the mobile technology over the reported existing weaknesses, could represent a bridge linking the patients to the physician, providing the latter with a more realistic snapshot of the patient's health status in order to tailor therapeutic pathways to patients' requirements, while shading light on their affordability and or sustainability.

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