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ORIGINAL ARTICLE

Introduction of a uniform record keeping practice for rheumatology clinics in Sri Lanka—an ILAR project

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Abstract

In Sri Lanka, record keeping in rheumatology clinics is purely paper-based. Clinic record books are given to patients, and the hospital does not retain clinical data. Different clinics and different rheumatology specialists practice different formats of record keeping in Sri Lanka. This project was aimed to develop a uniform record keeping system which can be used in all government rheumatology clinics in Sri Lanka. Project was carried out in two phases. First phase was carried out in seven rheumatology clinics to identify deficiencies in existing practice of record keeping in rheumatoid arthritis (RA), spondyloarthritis (SPA), and systemic lupus erythematosus (SLE). Second phase was to develop new clinic documents and a computer-based system, using the findings of the first phase. Recording of classification criteria at the time of diagnosis was 40.6% for RA and 90.3% for SLE. Initial clinical notes were not available in 18.3% of RA patients. Recording of individual classification criteria in SPA was ranged between 10% and70%, and it was 100% for arthritis. During second phase, new paper-based and computer-based record keeping systems were developed. Existing practice of record keeping is incomplete, especially in RA and SPA. The necessity of new, uniform record keeping system was recognized. Paper-based and computer-based record keeping systems acceptable to specialist rheumatologists, medical officers, and the Ministry of Health were developed and tested. The newly developed paper-based system is being used nationally while the electronic system is yet to introduced.

Keywords Classification criteria · Computer based · ILAR project · Record keeping · Rheumatology · Sri Lanka

Background

In Sri Lanka, healthcare is delivered through government and private providers. Government health care delivery, both inpatient and outpatient situations, is totally free. Patients can get investigations and treatment for free of charge. Most of the medications and investigations are available in the government hospitals. In the government health system, specialized care is provided through different hospital levels: base hospitals, district general, general hospitals, provincial general hospitals, teaching hospitals, and some selected specialized hospitals. Non-specialist hospitals are the divisional hospitals and primary medical care units [1, 2]. Rheumatologists provide their services in all teaching hospitals, provincial general hospitals, and most of the district general hospitals. At the end of 2017, total number of rheumatologists in the government health services was 29, while 9 were in the private sector for a total population of 20 million. A rheumatology clinic is generally run by a single rheumatologist. As the government policy, consultants appointed to a non-teaching hospital can serve in that hospital for a maximum of 4 years, and after which, he/she has to move to a news hospital on transfer.

Patient registration, record keeping, and referrals are all paper-based, and there is no designated clerical staff in the clinics. Details on clinical information and treatments prescribed are written on a book which is taken home by the patient allowing a possible risk of losing all clinical data if the patient misplaces the book. Except for personal details collected at first registration, no clinical information are retained in the clinics.

There is no uniformity in record keeping. Different rheumatology clinics used to adopt their own record keeping methods. As a result of compulsory transfer system for consultants, record keeping could vary under different rheumatologists in the same clinic at different points of time. All clinical details are handwritten by medical officers, and there are no standard

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printed materials for data recording. Generally, the rheumatology clinics are busy with a large number of patients attending regularly. Time available to spend with a patient depends on multiple factors including the number of patients attending the clinic and the number of medical officers designated to a clinic. Documentation of important clinical details is largely dependent on the above factors. Difficulties in monitoring the disease and recruiting patients for researches based on incomplete clinic notes have been identified as an area for early intervention.

There are no published data available for prevalence of rheumatological diseases in the country. Only data available are the data collected by individual rheumatologists and shared through personal communications. These deficiencies in record keeping had been discussed among rheumatologists in many forums including council meetings of the College of Specialists in Rheumatology & Rehabilitation-Sri Lanka (CSRRSL). The introduction of a new data recording system was a long-felt need to improve record keeping there by enabling easy reference, accurate decision making, promoting research, and establishing a national data base. Lack of funding and difficulties in establishing a dedicated office for this purpose were identified as major obstacles.

This project was carried out to address these already-identified issues with the aim of formulating a uniform record keeping method to all rheumatology clinics and establishing a national rheumatology data registry. The project was supported by the International League of Associations for Rheumatology (ILAR) project grant for 2017.

The project

Three major rheumatological conditions (RA, SPA, and SLE) were selected on the basis of importance of having accurate record keeping in diagnosis, monitoring, and follow-up. These chronic diseases require prolong record keeping compared to soft tissue rheumatism. Osteoarthritis (OA) was not included considering relatively little close monitoring required compared to other major rheumatological diseases. Only three rheumatological conditions were selected based on clinical importance of these diseases and the possible adverse effects on routine clinic work by introduction of too many changes at once. The project was carried out in seven rheumatology clinics in the Southern and Western provinces of Sri Lanka. The Western and Southern provinces have 5.9 million and 2.5 million population, respectively. These clinics are run by the most senior consultant rheumatologists, and they had the largest patient base. The feasibility of collecting data, communication, and transport was also considered in selecting these clinics.

Aim, objectives, and methods

Aim of the project was to identify the extent of the already-recognized deficiencies in the current record keeping practices and to introduce uniform record keeping system to rheumatology clinics in Sri Lanka.

The project was carried out to study current practice of how the classification/diagnostic criteria are recorded in clinic notes of patients with RA, SPA, and SLE and to study the prevalence of these diseases in rheumatology clinics. The other objectives are to introduce a uniform paper-based and a computer-based clinical record keeping method for rheumatology clinics nationally and to improve recording of criteria in clinic notes.

The project was started in January 2017. The project coordinator, a pre-intern medical officer, was employed to run the project office at the department of rheumatology and rehabilitation of Teaching Hospital Karapitiya (THK) and to coordinate the activities in the seven-selected clinics.

Project was carried out in two phases (Fig. 1). First phase was to gather and analyze data to identify the magnitude of deficiencies in current clinic record keeping practice. During the next phase, new data recording system was designed. Deficiencies identified during first phase were considered in developing the new system. This new system will be introduced to all rheumatology clinics in Sri Lanka.

Workshops were conducted for consultants and doctors of the selected rheumatology clinics. These workshops were designed to educate participants about the project and project objectives. Discussions were held regarding current international practicing criteria for selected rheumatological diseases, issues related to current practice of record keeping, and personal experiences of day-to-day clinical practice. Based on these discussions, data sheets were designed to gather information to study current practice.

Data sheets contained patient's demographic data, how the classification criteria were recorded at the time of making the diagnosis, and how disease activity scores were recorded in clinic notes. RA data sheet included items of classification criteria from the 1987 American Rheumatism Association (ARA) revised criteria [3] and the 2010 American College of Rheumatology/European League Against Rheumatism (ACR/EULAR) criteria [4]. SLE data sheet included all items of classification criteria from 1982 revised ACR criteria for SLE [5] and 2012 Systemic Lupus International Collaborating Clinics (SLICC) criteria [6]. SPA data sheet included all items of Assessment of SpondyloArthritis International Society (ASAS) classification criteria for peripheral and axial spondyloarthritis [7, 8]. These data sheets were first introduced as a pilot project to THK, Rheumatology and Rehabilitation Hospital Ragama (RRH), and District General Hospital Gampaha (DGHG) for a period of 1 month. After several modifications, final data sheets were used in all seven clinics selected for the project.

Data were collected during routine clinic visits from all patients diagnosed as having RA, SLE, or SPA. This was carried out for a period of 3 months. In Sri Lanka, drugs are

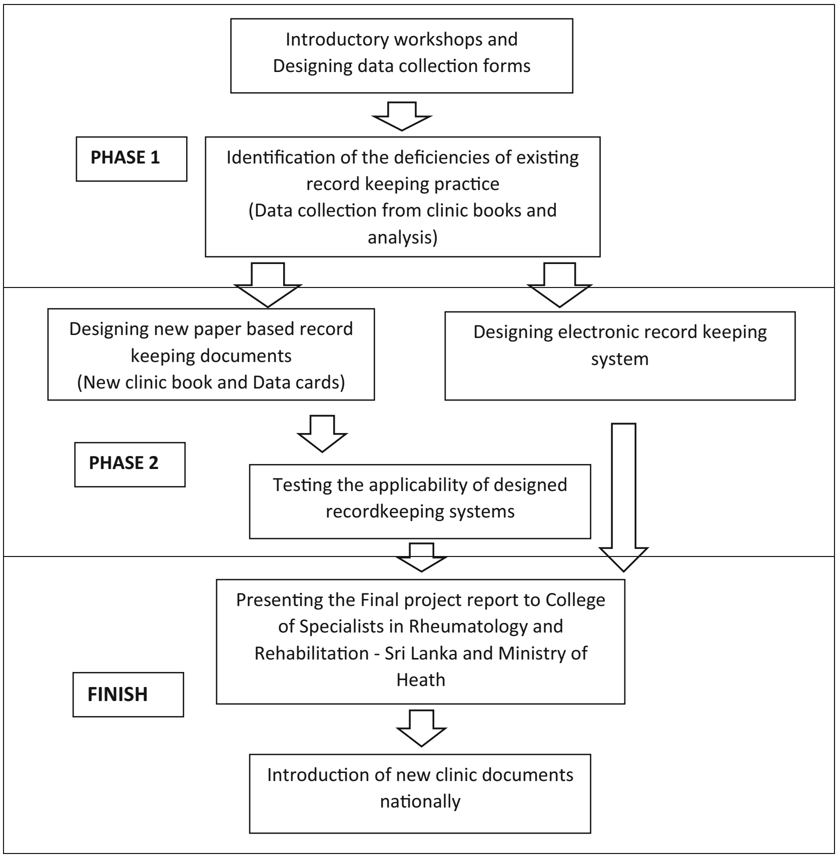

Fig. 1 Phases of the project

issued from hospital free of charge to patients as a national policy. These medications can be prescribed only for a maximum period of 1 month. Therefore, patients have to come to clinic at least once a month to collect their medications. It was expected that data from almost all patients would be collected during this 3-month period.

The consultant rheumatologists and medical officers attached to clinics were involved in the data collection. Information regarding the recording of clinical criteria and diagnosis were gathered from initial clinic notes from the time of first registration at the clinic up to the time of making the diagnosis. Retrieving information from current clinic documents was difficult and relatively time consuming. Some of the clinic notes carried by patients were more than 10–15 years old. Completed data sheets from all seven clinics were collected at the project office. Consultants of the seven clinics met regularly to discuss and assess the progress of the project. Progress of the project was reported to the council meetings of the CSRRSL. Data gathered from all clinics during the 3-month period were analyzed and presented in Tables 1, 2, 3, 4.

Based on the above findings, new clinic documents were designed to address the deficiencies identified. Three single-paged data sheets were designed to record information from patients with RA, SPA, and SLE which will be filled at the time of making the diagnosis. Another document was designed to gather basic demographic details and the diagnosis for all patients registered at the clinic. Classification criteria were printed in these documents for easy reference and accurate diagnosis. These documents will be retained in the clinic.

The following classification criteria were used in data sheets; 2010 ACR/EULAR criteria for RA, 2012 SLICC criteria for SLE, ASAS classification criteria for peripheral spondyloarthritis, and modification of the Berlin algorithm for axial spondyloarthritis [7–9]. Disease activity score at diagnosis was also recorded. Clinical Disease Activity Index (CDAI) for RA [10, 11], Systemic Lupus Erythematosus Disease Activity Index, 2000 (SLEDAI 2K) for SLE [12], and both Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) and ASAS-endorsed disease activity score (ASDAS) in SPA [13–15] were included in new documents. These newly designed new clinic documents will be kept in the clinic with the aim of transferring data to an electronic database subsequently. Preliminary electronic data collection software has been developed. Discussions as to how this will be introduced to government hospitals are being held with the Ministry of Health.

A new clinic book of 80 pages was designed to use in all clinics which will replace the current clinic book. This book was designed to document patient's socio demographic data, classification criteria for the above three diseases at the time of making the diagnosis, and disease activity scores during subsequent clinic visits. It also contains a list of routine and

Table 1 Age and sex distribution of SLE, SPA, and RA

	Number	Sex distribution		Mean age (in years)	Age range (in years)
		Female	%		
SLE	124	118	95	31	13–56
SPA	201	132	66	43	17–74
RA	2889	2542	90.4	50	15–87

special investigations in table form which can be used for 36 subsequent clinic visits providing a quick visual assessment of the trends during clinic visits. The rest of the pages are for documentation of daily states during clinic visits. This book will be given to the patient at the time of first diagnosis.

Results

These are the results gathered to identify the extent of the deficiencies in existing record keeping system. Initial clinic documents were not available for data collection in 18.3% of RA patient population. Distribution of the patients according to the disease, sex, and the age are shown in Table 1.

When the clinic notes clearly documented that the classification criteria met with appropriate score for RA and SLE, they were considered as records of classification criteria fulfilled. 40.6% clinic records of RA patients documented that the diagnosis of RA was made after fulfilling classification criteria. This was 90.3% in the case of SLE. Individual classification criteria were documented in clinic notes of RA, SLE, and SPA patients and are presented in Table 2, Table 3, and Table 4. It was difficult to ascertain whether classification algorithms were followed or not at the time of making the diagnosis of SPA. It appeared that the diagnosis of SPA was made on the basis of overall clinical judgment more than adhering to application of classification criteria. Therefore only individual classification criteria that were recorded were analyzed in SPA.

Table 2 Documentation of individual RA classification criterions in clinic notes at the time of diagnosis

RA (total number 2889)

Criterion	Number recorded[1]	% recorded (± 95% CI)
Involved joints	2223	77% (± 1.53%)
Rheumatoid nodule	695	24% (± 1.56%)
Rheumatoid Factor	2016	73% (± 1.62%)
ESR	2289	79% (± 1.49%)
CRP	760	26% (± 1.60%)
Anti CCP Ab	55	02% (± 0.51%)
X-ray	965	38% (± 1.77%)

RA, rheumatoid arthritis; *CI*, confidence interval; *CRP*, C-reactive protein; *ESR*, erythrocyte sedimentation rate; *Anti CCP Ab*, anti-cyclic citrullinated peptide antibody

[1] Recording of the particular criterion in clinic notes (irrespective of its positivity or negativity and presence or absence) was considered as recorded. If the criterion was not mentioned in the clinic notes or if the initial clinic details were not available for analysis, they were considered as not recorded

Discussion

Introduction of a new record keeping system is a long-felt need. Except for efforts to collect data from individual clinics, no attempt has been made to develop a national rheumatology database. It was not possible to find similar projects of this nature. Concerns about the poor record keeping in rheumatology clinics were proven real by this study. Current practice of record keeping is incomplete in RA and SPA, while documentation of classification criteria for SLE was 90.3%. Paucity of rheumatologists in the country (1 per 500,000 population), inadequate number of medical officers, absence of clerical staff, and large patient population in rheumatology clinics are some factors contributing to deficiencies in these busy clinics. Since all clinic notes need to be handwritten, traditional practice was to document as minimum details as possible in clinic notes as a measure of saving time. Even though the classification criteria applied at the time of diagnosis, these are not recorded in clinic notes most of the time. Project aim was to correct this deficiency by making a printed clinic book available with classification criteria as a visual guide and to record them.

Diagnosis of rheumatological diseases is generally made on best overall clinical judgment and application of classification criteria. Conducting studies retrospectively to analyze data from patients' clinic notes, which is the only source of such data, is a problem with current practice of record keeping.

Regular updates on the progress of the project activities were provided to the council of CSRRSL. The council approved the implementation of newly developed clinic documents including the clinic book in all clinics in the country. It is expected that provision of printed documents with classification criteria at the time of making diagnosis will improve the accuracy of diagnosis. These paper-based documents are

Table 3 Documentation of individual SPA classification criterions in clinic notes at the time of diagnosis

SPA (total number 201)		
Criterion	Number recorded[1]	% recorded (± 95% CI)
Inflammatory back pain	133	66% (± 6.55%)
Involved joints	201	100% (± 0%)
Enthesitis	140	70% (± 6.34%)
Uveitis	13	06% (± 3.28%)
Dactylitis	132	66% (± 6.55%)
NSAIDs response	46	22% (± 5.73%)
HLA B27	58	29% (± 6.27%)
X-ray changes	90	43% (± 6.84%)
MRI changes	21	10% (± 4.15%)

SPA, spondyloarthritis; *CI*, confidence interval; *NSAIDs*, non-steroidal anti-inflammatory drugs; *HLA-B27*, human leukocyte antigen,

[1] Recording of the particular criterion in clinic notes (irrespective of its positivity or negativity and presence or absence) was considered as recorded. If the criterion was not mentioned in the clinic notes or if the initial clinic details were not available for analysis, they were considered as not recorded

being used in all clinics in the country since February 2018 as an ILAR-CSRRSL initiative. This is the first time an island-wide data recording was attempted in rheumatology clinics in Sri Lanka. CSRRSL had discussions with the Director General of Health Services (DGHS) and Director, Health Information (DHI) of Ministry of Health to implement the project proposals with the aim of establishing a uniform rheumatology record keeping system.

An important limitation of this project was not selecting all clinics in the country for data collection. This was not possible due to work load in clinics which does not allow time to involve in project with a wider coverage. Traveling to these centers especially situated in suburbs is difficult. Most of the clinics in the peripheries are newly established units and has no significant patient population.

Development of a computer-based record keeping system in a resource poor country like Sri Lanka is challenging. It is expected that with the introduction of new record keeping system, application of classification criteria when making a clinical diagnosis would improve. Development of local diagnostic and management guidelines and implementation of a national rheumatology data registry in achieving excellence in rheumatology services in Sri Lanka are long-term extended outcomes of this project.

Conclusion

It was concluded that existing practice of record keeping in rheumatology clinics is not satisfactory especially with regard to recording of classification criteria. Based on these

Table 4 Documentation of individual SLE classification criterions in clinic notes at the time of diagnosis

SLE (total number 124)		
Criterion	Number recorded[1]	% recorded (± 95% CI)
Acute or Sub acute cutaneous lupus	82	66% (± 8.34%)
Chronic cutaneous lupus	96	77% (± 7.41%)
Oral ulcer	79	64% (± 8.45%)
Alopecia	114	92% (± 4.78%)
Synovitis	109	88% (± 5.72%)
Serositis	99	80% (± 7.04%)
Renal	79	64% (± 8.45%)
Neurologic	99	80% (± 7.04%)
Hemolytic anemia	87	70% (± 8.07%)
Leukopenia	102	82% (± 6.76%)
Thrombocytopenia	114	92% (± 4.78%)
ANA	120	97% (± 3.0%)
Anti dsDNA Ab	49	40% (± 8.62%)
APL Ab	73	59% (± 8.66%)
Low complement	40	32% (± 8.21%)
Direct coombs	22	18% (± 6.76%)

SLE, systemic lupus erythematosus; *CI*, confidence interval; *ANA*, anti-nuclear antibody; *ds DNA*, double stranded DNA; *APL Ab*, anti-phospholipid antibody,

[1] Recording of the particular criterion in clinic notes (irrespective of its positivity or negativity and presence or absence) was considered as recorded. If the criterion was not mentioned in the clinic notes or if the initial clinic details were not available for analysis, they were considered as not recorded

observations, new paper-based clinic documents were introduced and currently being used in rheumatology clinics. Preliminary electronic data collection software has been developed. Discussions as to how this will be introduced to government hospitals are being held with the Ministry of Health.

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Compliance with ethical standards

Disclosures None.

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