





## Coordinated transitional care of N. Greek pediatric SLE patients: could it be improved? Study name PASSAGE (**P**edi**A**tric **S**ystemicLupu**S**: **T**r**A**nstition in Northern **G**re**E**ce)

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### ABSTRACT

Transition is the organized, stepwise process involving the transfer from the pediatric-centered health services to the adult-centered care. It is a holistic, multi-dimensional, multi-disciplinary and active process that addresses the medical, psychosocial and educational/vocational needs of adolescents. The objective is to evaluate the eligibility of the existing transition model held by the Greek Pediatric Rheumatology Referral Center, located in the First Department of Pediatrics, Aristotle University Thessaloniki, to detect potential indices for further improvement.

Methods: a) Education on the process of transitional care and subsequent evaluation of the current transition model; b) depiction of adolescents and young adults population with pSLE in the participating settings by updating the existing pSLE registry; c) support regarding the self-management of pSLE patients; and d) familiarity with the pSLE-young adults' settings through a virtual tour in the adult care setting and staff presentation.

### The importance of the study:

The development and documentation of a coordinated, structured multidisciplinary, evidence-based, transitional care program. This stepwise transition process will lead to a clear-cut written policy for the optimal transition according to each pSLE patient's needs. The severity and outcome of each individual patient may be unique, but can be manageable.

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## BACKGROUND

Transition is the organized, stepwise process involving the transfer from pediatric-centered health services to the adult-centered ones. It is a holistic, multidimensional, multidisciplinary and active process that will manage adolescents' medical, psychosocial and educational/vocational needs.<sup>1,2</sup>

The aim of the transition is not merely the patient's smooth integration in the new environment: it aims to empower the patient so that he/she undertakes his/her personal health and lifestyle responsibilities. These skills will facilitate the optimum lifelong physical and bio-psychosocial functionality, and the fulfilment of the individual's maximum potential.<sup>3-5</sup>

The importance of a comprehensive plan for the transition of patients with chronic diseases is widely recognized. It is based on the trifold "Health - Physical Limitation-Somatic Function" and has a beneficial effect on improving the quality of life over the disease course.<sup>1,6</sup> Conversely, failure of this scheduled procedure lurks the potential of maladjustment to the new care setting, with subsequent poor compliance and a further impaired quality of life.<sup>3, 6-8</sup>

Several Organizations such as the American Academy of Pediatrics and the British Society of Paediatric and Adolescent Rheumatology continuously update guidelines for a successful transition.<sup>1,4,9-11</sup>

One of these transition models "transfers" the patient to the Outpatient Clinic for adults, following the certified awareness on the disease self-management, the capacity to live independently from the family, and his/her preceding acquaintance with the new medical environment. Another model is based on joint assessments by the pediatric Rheumatologist and adult Rheumatologist before transition, along with patients' gradual relevant training. In line to that, a third one offers periodic joint assessments by both Rheumatologists in an exclusively Adolescent Rheumatology Clinic.<sup>1,4,10</sup>

The choice of the proper transition model depends on the performance of routine clinical practice under the existing settings, time limitations related to the transition process and disease particularities.

Finally, the stakeholders of the transition process should have the essential knowledge and skills regarding the characteristics of the chronic illness during adolescence.<sup>8-10,12-14</sup>

## ESSENTIALS ON PEDIATRIC SLE

### Definition-demographics:

Pediatric SLE (Childhood onset SLE or pediatric SLE, p-SLE) which was earlier named juvenile SLE (juvenile SLE), is SLE with an onset prior to 18 years.<sup>15,16</sup>

It represents 15-20% of the overall SLE cases and the median age of onset is 12-15 years. The incidence is estimated to be 0.3-0.9 cases/100,000 pediatric population and the prevalence 3.3-8.8/100,000, respectively. It is a prototype of chronic diseases, characterized by lifelong frequent flares and minimal periods of remission off-treatment.<sup>15-17</sup>

## DIFFERENCES IN THE PHENOTYPE BETWEEN pSLE AND ADULT SLE

pSLE is characterized by a more severe morbidity than in adults; namely, a more aggressive invasion and graver activity in the disease course.<sup>15,17</sup> The various manifestations mimic several adolescent diseases, including infections, malignancies, psychiatric disorders or drug abuse.<sup>15</sup> The disease impact regarding the body image and the psychosocial health of adolescents are unfavorable determinants affecting the management of pSLE by the patient and family and the disease acceptance by his/her surroundings.<sup>6,7,17-20</sup>

## PROBLEMS OF THE ADOLESCENT WITH pSLE FROM DIAGNOSIS UNTIL TRANSITION

Since the announcement of the diagnosis, the adoles-

**Table 1.** Impact of pediatric SLE to patient and family

### 1. Impact on the patients

Physical or mental symptoms derived either from the chronic disease or the treatment or the damage development:

- Bad mood or even body image rejection
- Frequent class absences due to disease activity or follow-up visits, leading to impaired academic performance
- Absences from sports, extracurricular activities or peer gatherings due to disease activity or physical disability. They may result in a reduced or disturbed sociability

### 2. Impact on the family members

- Shrinking of the personal time, changes in the conditions of the family life or the work due to:
  - A. Continuous (un)scheduled follow-up visits or hospital admissions
  - B. Direct or indirect involvement in the access or administration of the pSLE treatment
  - C. Continuous stress, deranged family dynamics, financial consequences

cent and family are invited to a stepwise educational training aimed to accept and manage the disease.<sup>4,21-24</sup> The impact of pSLE on individuals and families depends on the disease *per se* as well as the impact of treatment (Table 1).<sup>16,18,25,26</sup> Additionally, despite improved management of pSLE over the last decades, the development of damage remains an unavoidable condition, which, combined with persistent activity, unfavorably affects the patients' and their families' quality of life.<sup>19, 26,27</sup>

### CHARACTERISTICS OF ADOLESCENTS WITH pSLE

Over adolescence, physical and hormonal changes make numerous adolescents believe that they are "omniscient", fearless and infallible; factors that potentially prime a poor pSLE management.<sup>5</sup> There are supplementary conditions that can deregulate the disease process and lead to an unplanned change of health-care providers, such as change of residence due to either educational or working needs, insurance coverage, or development of relationships with the other gender and upcoming pregnancies.<sup>10,12,13,16,20-23</sup>

### RESEARCH PROPOSAL

#### Hypothesis:

The suitability of the existing transition model for pSLE patients who are being cared by the Referral Center and its potential enhancements.

#### Methods

The limited time frameworks allocated per patient as a result to bureaucracy or to the understaffing of the Reference Centre, have imposed a program consisted of the following transition steps:

- a) **Preparation for transition:** The springboard for the onset of the transition process is the announcement of the diagnosis and notification of the lifelong necessity for specialized medical care. Especially in pSLE, as the diagnosis is established during adolescence, the time interval up to the final transfer to the adult-oriented Clinic is rather short.
- b) **Evidence-based information of the stakeholders:** The ongoing developments regarding an early recognition and treat-to-target therapies of the different pSLE phenotypes necessitate continuing education.
- c) **Highlighting the risks deriving from poor compliance or follow-up discontinuation.** Adolescence is dominated by a trend of dispute and rejection of rules. Especially in pSLE, compliance is necessary as some "insidious" findings, clinical or laboratory, cannot be evaluated by non-physicians. Therefore, patients are encouraged to create a diary (paper or electronic) which will include his/her contact information with the caring physicians and data

about monitoring and treatment. This practice aims to gradually involve patients in their own self-management of pSLE.

- d) **Discussion on psychosocial issues.** It is well-known that pSLE is the principal rheumatic disease which commonly affects emotion or higher cognitive dysfunction, such as synthesis of ideas, and vocational and social rehabilitation. Thus, patients are encouraged to participate in meetings with specialists in order to be supported in the choice of a personal or professional lifestyle which will be compatible with the limitations imposed by pSLE.
- e) **Access to reliable information.** Online education, which is popular amongst adolescents, can be recommended, as long as the provided data concern Caucasian patients.
- f) **Relevant information and interconnection with the adult Rheumatologist.** The necessity of transition is explained to the patients. The main reasons are existing legislation regarding the authorization for electronic prescriptions in adulthood, the solution of adults' specific problems and the issuance of medical certificates for military or professional use. Patients are furthermore ensured that they are not abandoned by their "family" pediatric Rheumatologist, but that they are being transferred to settings that will contribute to the development of self-confidence and optimism for future and their independence, too.
- g) **The final day of transition to the adult-oriented Clinic** The patient along with the parent(s) and the pediatric Rheumatologist arrive at the new settlement. A preceding medical report outlining the phenotype of the particular patient has already been studied by the physicians to help the adult Rheumatologist pre-schedule the first "official" personalized assessment of the new patient.

### MODES OF APPROACH AND REPLY TO THE RESEARCH HYPOTHESIS

#### A. Education on the transition and evaluation of the current model

Data following the patient's integration from the existing settings to the adult-focused ones, as well as the adequacy of this procedure, are lacking. The number of our pediatric patients who have remained in the adult Clinic or have switched to another care provider or have discontinued their further monitoring and the relevant reason(s) for this are unknown. This is a significant evaluation that will lead to the documentation of stakeholders' experiences and may prevent unfruitful patient-staff cooperation in the new medical environment.

**Suggestions:****1. Online education of patients with pSLE and their guardians, for those who have already been incorporated in the adult settings, depending on the significance of the transition.**

It may be a slide presentation with pictures, that can be saved and downloaded by the stakeholders. This presentation will be a comprehensive tour through the transition process in terms of necessity and stakeholders' preparation. Understanding the transition steps is crucial for the successful completion of the care transfer and its future evaluation.

**2. Evaluation of the transition process by a specific questionnaire on the portal of Pediatric League Against Rheumatic Diseases (paa.gr).**

The development of a relevant evaluation questionnaire that will be answered by all stakeholders involved in the transition, namely health professionals and patients. This will generate a database that may lead to revisions of the transition process and will include additional items to assess the patient and staff preparation for the achievement of transition. Furthermore, it will rate their satisfaction from this process (overall satisfaction score).

This questionnaire will be online in order to be accessible and able to be completed by anyone, regardless of his or her place of residence.

**B. Hiring and training a nurse on pSLE**

He/she will be the liaison of the two Clinics; his/her duties will include the organization, coordination, supervision and recording of the patients' smooth transition and integration process.

**C. Depiction of the adolescent/young adult population being cared for in the project's settings.**

This registry will be an extension of the patient's existing electronic recording in respect to their disease course after joining the adult setting; furthermore, it will enroll additional young adult patients. Patients will be recorded in the existing registry of the Pediatric Rheumatology Center, using the contemporary evaluation pSLE tools as indices. Prior to any patient's registration, an informed written consent/assent will be obtained for future work-ups or screening tests, which will also highlight the confidentiality of the information provided by the patient.

**D. Support of pSLE self-management:****1. Experiential interaction of adolescents/adults with pSLE by creating a patients' online forum for exchanging experiences/views.**

Information regarding the existence of the forum will be diffused via the portals [www.paa.gr](http://www.paa.gr) and [www.tosomasoumilaei.gr](http://www.tosomasoumilaei.gr). Registration to this online forum pre-requires consent.

**2. Online education of pSLE patients and families, their friends, educators, and school counselors through the paa.gr portal.**

The update of the Greek language information for pSLE which has been uploaded to the PRINTO portal (Pediatric Rheumatology International Trials Organization) will be the preliminary information about the disease. This text has been written by PRINTO members, including the undersigning researchers and derived by a consensus. A link will be created that will direct to the relevant pSLE page as well as to the Greek SLE webpage (<http://www.tosomasoumilaei.gr/ΣΥΣΤΗΜΑΤΙΚΟΣ-ΕΡΥΘΗΜΑΤΩΔΗΣ-ΛΥΚΟΣ/>). These sites will invite the public to visit them in order to effectively contribute to patients' social support.

There will be also a separate page addressed to school staff to help them manage the pSLE student. At the bottom, a metric evaluation scale (0-10) will be accessible to assess the usefulness and the provided support of this online information, as well as the potential uploading of relevant suggestions for its improvement in respect to missing domains.

The development and uploading of a video with a mock interview between a patient-physician pair performed by healthy actors will also take place. This explanation will be visible at the bottom of the website. It will discuss the experience regarding the gradual education on the pSLE self-management and the concomitant difficulties of everyday life.

Validated Greek versions from specific and general questionnaires assessing the quality of life in patients with pSLE, as Simple Measure of Impact of Lupus Erythematosus in Youngsters (SMILEY), Short Form 36 (SF36), General Health Questionnaire (GHQ) will be uploaded. They will allow the patient's self-evaluation, regardless of the follow-up visit. This application will be created for smartphones and data shipping.

**3. Psychological support - Vocational guidance and legal counseling for patients with pSLE**

1. A child Psychologist with experience in adolescence will act as patient counselor; online patients' sessions will also be feasible.

2. Web data will be created regarding the selection of vocational directions in respect to pSLE characteristics. A professional counselor will also be available to organize sequential sessions, to inform and run related tests. The derived results will be e-mailed to the Centre. The vocational counselor will be able to collaborate with the relevant State local Centre(s) (KESYP, where available) in order to promote the best to the patient's counseling.

3. Uploading and interpretation of the current

legislation on insurance and educational issues affecting pSLE patients.

**E. Familiarity with care settings oriented to young adults with pSLE by a virtual tour in the adult Rheumatology Outpatient Clinic.** It will present the staff that will concomitantly welcome the young adult to their setting.

### ANTICIPATED BENEFITS

A successful transition ensures a better survival and conservation of the quality of care. The evaluation of the current transition process, the ongoing collection of pSLE patients' and families' real life, the stepwise training of the patient-family and social environment will serve to update the current transition procedure. In parallel, the first assessment regarding the support provided to patients with pSLE through the portals [tosomasoumilaei.gr](http://tosomasoumilaei.gr) and [paa.gr](http://paa.gr) will be acquired.

A multidisciplinary, structured transition with allocated responsibilities will take place. It will involve physicians, a nurse, an electronic programmer, a data administrator, a psychologist, a vocational counselor, a solicitor and a secretary.

During the last few decades, the improved outcome of pSLE patients allowed more patients to reach adulthood and have lighter functional impairment. However, they still carry residual psychological and social dysfunctions, which are reflected in the academic, family and workplace.

Thus, the depiction of the impact of pSLE on the life of these patients will detect modifiable risk factors and will identify those patients with a poorer outcome risk.

**Outcome of the project:** The creation and registration of a stepwise transition, the Center's policy. This will lead to the optimal personalized pSLE transition procedure, as the severity and outcome of each patient may be an unpredictable, but a manageable matter.

### CONFLICT OF INTEREST

The authors declare no conflict of interest.

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