in hospital and profound long term health consequences. It charts a journey to a more effective model of treatment and self-management. This now sees her largely symptom free, on minimal lupus medication (blood pressure tablets) and leading an active personal and professional lifestyle.

Mary draws from her four decade experience to suggest a model of doctor - patient communication, collaboration and partnership that has implications for improving outcomes and quality of life for all lupus patients.

Methods

- Giving the patient a voice. Understanding the powerful psychological benefits with consequential direct and indirect physical benefits for the patient when they are regarded as an “equal partner”, an active as opposed to a passive participant in the treatment journey.
- Importance of information sharing with the patient, the treating immunologist and the general practitioner.
- Understanding that the fluctuating and multi-organ nature of lupus symptoms means that treating obvious presenting symptoms without understanding and treating the underlying auto-immune causes can and does lead to treatment errors and adverse patient outcomes.
- Addressing the whole patient, their physical, mental and emotional wellbeing, and the general hormonal system can greatly reduce ongoing symptoms and acute flares.

Results Improved patient outcomes.

Conclusions A more effective model of care.

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**The Italian SLE Survey by Web: Investigating Patients’ Unmet Needs with Online Survey Tools**

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Background and aims Chronic illness perception and difficulties in everyday life due to disease and medications were explored by the first italian ONLINE SLE SURVEY, designed to assess chronic pain impact and health-care provision quality in Italy.

Methods Online questionnaire was created through Qualtrics, setting geographic data, disease duration, age at diagnosis, comorbidity, disability degree, care practices, treatments, subjective incidence and characteristics of pain. SLE patients were advertised by social media. Participation was voluntary and anonymous.

Results 550 SLE patients provided complete data; F 94.7%, M 5.3%; mean age 33 y. (14–82 y.); first SLE diagnosis at mean age 29 y.: 84% received SLE diagnosis between 18–42 y.; 36% comorbidity with other (1-6) autoimmune conditions. SLE impact on life is relevant, with specific problems and needs at different disease stage. Stress of life: relevant and worsening illness conditions; frequent relational problems.

Need for psychological support: 54%. Osteoarticular pain is main symptom condition (83%), but only 54% use drugs for pain control. Physicians seem not responding to patients’ request to take into account impact of pain. Women workers face many difficulties due to many combined factors which severely reduce access to proper care

Conclusions Health-care current model doesn’t allow respect of SLE patients complex needs: most remain dissatisfied, affecting quality of life and doctor-patient concordance. SLE SURVEY highlights importance of competent clinical listening by physicians and capacity to hold patient’s crisis. GRUPPO ITALIANO LES – a volunteer patients’ organisation - established ONLINE SLE SURVEY practice to explore current facets, development of patients’ needs, and set social-health policies.