

COMMENTARY:
PEDIATRIC RHEUMATOLOGY IN TIMES OF CRISIS

At the end of 2001, Argentina developed the most severe socioeconomic crisis of its history. After a long period of stability, an economic crisis with a sudden devaluation of the Argentine peso resulted in increased poverty, unemployment, and severe social unrest. Health care was not exempt. Indeed health care is one of the areas where the impact of this crisis has been most evident. This commentary highlights the strategies we've used to deal with this crisis in order to best help our patients. These lessons may be applicable to other pediatric rheumatology centers in other countries with a sudden economic crisis or similarly limited resources and funding.

MEDICAL INSURANCE

Since the unemployment rate reached more than 25%, many people were no longer eligible for the medical service or insurance previously provided by their trade unions. People were too poor to afford private medical insurance that would help pay for these medical services. Eventually more than 50% percent of the population fell into poverty with difficulty even getting enough food. Many poor families could no longer afford to pay the bus fares to their scheduled visits in public hospitals. Surprisingly, a different patient population had begun to replace them and overcrowd the public hospital service: the newly impoverished and unemployed middle class.

HOSPITAL CARE

My hospital, Hospital de Pediatría Pedro de Elizalde, is one of the public pediatric hospitals of Buenos Aires and we have had to deal with this sudden change. We are seeing more new patients due to the movement of families from the private health care system into public hospitals. We were faced with several major changes as our working class patients were less and less able to come to the hospital for care and the new middle class hospital population had different expectations of the medical care provided.

Remarkably, we began to see a change in the types of rheumatic diseases and syndromes we were seeing. In particular, the increase in pain amplification syndromes was extraordinary including fibromyalgia and erythromelalgia. These children usually belonged to ex-middle class families, and their pain was associated with severe emotional distress. Tension and depression were rife among family members, and pain, perhaps as an expression of the societal and family crisis, was the most outstanding feature. We began to work very closely with the psychiatrists and psychologists at our hospital, and with the Adolescent Unit staff. They referred to our Section all patients that consulted them because of emotional symptoms and at the same time complained of severe joint and/or muscle pain.

Unfortunately the human, medical, and financial resources of the hospital were not increased to keep up with the increased number of patients, overcrowded consulting rooms, and an inability to schedule patients to regular appointments. As indigent families often did not have enough money for transportation on the day of any scheduled appointment, families could not reliably travel to our hospital on any appointed day. So since the crisis began,

children could not be seen at regularly scheduled visits for our rheumatology clinic. We have followed our patients without scheduled visits on a first come, first serve basis. This change often has led to crowded, congested waiting areas, long waits to see the physician, greater difficulty coordinating medical care, and increased stress for everyone.

Due to financial constraints, physicians have had to limit the use of laboratory tests or other studies. We still can order CBC's, liver function tests and urinalyses as routine tests for the initial diagnosis and later monitoring of disease activity and drug tolerability. The expensive serologic tests ANA, DNA, C3 and C4 have been restricted to severe cases, and other immunologic tests are only rarely ordered. This lack of available testing means that we must depend on the old-fashioned thorough history and physical exam as the most important tools for successful diagnosis and treatment.

OUTREACH

As a major pediatric referral center, we ordinarily are referred patients from all over Argentina. Since the economic crisis began, it became very difficult for these patients to get official economic support to come to Buenos Aires and spend days or even weeks in our center. Because many of our established patients were not coming to follow up, we decided to track down those children on immunosuppressive therapy through the hospital social service. We then referred these patients to medical facilities closer to their homes. We kept in contact with the local treating pediatricians via e-mail or telephone. In addition, we scheduled outreach visits to the provincial hospitals to follow up on these patients nearer to their homes. The team that

now travels to the provinces includes a pediatric rheumatologist and a physical therapist. This team spends two days in each city, and meets with patients and their pediatricians to establish plans for local treatment.

DRUG COSTS AND MEDICAL CARE

Many parents of our patients have put off or stopped their child's medical care or due to the cost of drugs and travel expenses to and from hospital. To better understand this problem, we polled the parents of our patients in August 2002. One hundred families were interviewed during a follow up visit after giving verbal informed consent. We found 62% of the parents had a regular job, 15% were under employed and 23% unemployed. The cost of drug treatment for this group was 170 US\$ as a mean- per month (range 0 – 500 US\$).

We decided to review the costs of drugs used in our Pediatric Rheumatology clinic compared with weekly family income before and after the peso devaluation. We calculated the costs of one day of treatment according to the usual doses of all the drugs (including biologics) for a 20 Kg body weight patient. We looked at two time points, December 2001 (before devaluation with an exchange rate 1:1 between US\$ and Argentine peso) and November 2002 after one year of devaluation (see next table).

COST OF DRUGS			
	December 2001	November 2002	% of change
Cost in pesos	\$91.-	\$ 151.79.-	+67.08%

Cost in US\$	US\$91.-	US\$ 43.36.-	-52.36%
FAMILY INCOME			
Salary in pesos	300.-	300.-	No change
Salary in US\$	300.-	85.71	-71.4%

According to these data, the cost of drugs in pesos increased almost 70%, but the family income did not change in pesos. This explains why many of our patients cannot afford arthritis treatment for their child.

Since most of our parents and families now could not afford the anti-rheumatic drugs for their children, social services in the provinces and counties provided the medications to some of our patients. Other families were referred for help from nongovernmental agencies such as Red Solidaria (Solidarity Net). Since methotrexate is not an expensive drug, families can afford it and we can use it. However, steroids are very expensive and we must admit some children to the hospital to give them periodic IV pulse therapy instead of oral steroids that are more expensive. Most of the patients that were receiving anti-TNF treatment continued it irregularly and some of them discontinued treatment.

Last August, government decreed that prescriptions must be generic. This edict led to a serious controversy because the generic drugs are not always the most effective because of bioequivalence issues. Many patients that changed to generic drugs had their disease become more active, or had more adverse events, making us suspect efficacy and safety problems. Fortunately, clinical drug trials have allowed some patients to be treated with

new and high quality drugs with very good medical control for safety and efficacy.

PHYSICAL THERAPY/ FUNCTIONAL OUTCOME SCALES

The need for physical therapy has increased because of the many new patients with arthritis and pain amplification syndromes. The physical therapists decided to group children together and work with a very intensive exercise program; the competition keeps the children very active and engaged.

Scales such as CHAQ, and CAPFUN, a functional ability scale we presented at the Park City IV meeting, show changes in disease status. We have used the data from these scales, to modify the drug and/or physical therapy treatments with very good results. Both scales can be performed in a short time and at no cost. We now rely on clinical findings more than ever. Perhaps this is not a complete evaluation for evidence based medicine, but in our time of crisis there are few options.

CONCLUSIONS

- Economic crisis and social displacement lead to decreased medical resources, impaired coordination of patient care, and an increased incidence of pain amplification syndromes.
- In difficult times, CBC, liver function tests, and urinalysis are often the only tests available for use in diagnosis and the monitoring of disease activity and drug therapy.

- Immunologic tests have to be restricted to a minimum and clinical diagnostic criteria used for diagnosis.
- Physical therapy is an important tool both for improving functional ability and pain relief.
- The drug of choice for JIA under our conditions is methotrexate- it is cheaper than other disease modifying drugs.
- Clinical drug trials under ethical conditions have been very helpful in times of economic crisis, allowing us to provide an excellent treatment with close monitoring of patient status.
- CHAQ and CAPFUN have become very important tools for evaluation of our patients in long term follow-up as they are inexpensive and correlate very well with the clinical state of the patients.

We remain frustrated that many children are no longer receiving needed treatment for their rheumatic conditions. We also are only to aware that we have very powerful drugs that we can not even consider offering them. The situation is often very difficult for the patients and their families. Our hands, eyes and ears have become our most powerful tools for diagnosis and follow-up. Fortunately, our love and compassion for children that are suffering, not only from their disease, but also the difficulties of an undeserved social crisis, have proven to have great therapeutic value.

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