Effect of oral iron chelation therapy with deferiprone (L1) on the psychosocial status of thalassaemia patients

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Abstract—β-Thalassaemia requires life-long treatment, including regular blood transfusion and daily iron chelation by desferrioxamine, which places considerable burden on the social and psychological life of patients. It is expected that oral chelation therapy, which is easier to administer, would improve their psychosocial status. In this study, interviews were conducted with a series of 44 patients recently placed on oral chelation therapy to evaluate their reactions to the new treatment. Eighty-six per cent of patients complied better with the oral chelation therapy. Fifty per cent of patients mentioned that relief from the desferrioxamine pump was the major improvement, while 47% felt psychologically better. Fifty per cent of patients noted improvements in their relationships, while 63% noted increased social activities. Evaluation of a larger sample of patients over a longer period of time is needed in order to confirm the favourable results obtained in this study.

Key words: Oral chelation; psychosocial status; thalassaemia.

INTRODUCTION

Most patients with homozygous β-thalassaemia have thalassaemia major, a clinically severe anaemia, which requires life-long treatment, including blood transfusion and iron chelation therapy. With the current standards of medical care, the survival and quality of life of thalassaemia patients have steadily improved. However, the life-long treatment, especially iron chelation therapy by subcutaneous infusions

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of desferrioxamine, for 8–12 h every night, at least 5 nights a week, places considerable burden on the social and psychological life of the patients and their parents [1, 2]. Oral chelation therapy would be expected to improve this psychosocial burden. Recently, the effectiveness of deferiprone (L1) as an oral chelator has been shown in some studies [3–5].

The Chronic Care Center is a Lebanese charitable institution established in 1993, where patients with thalassaemia and juvenile diabetes mellitus are followed up. It currently cares for over 500 thalassaemic patients, providing free medical consultations and follow-up, and subsidizing laboratory tests and the required medicine, including iron chelation. Psychosocial support is also available at the centre, through the department of social services and consultations with a psychologist, as needed.

The present study was conducted to evaluate the effect of the change in chelation therapy, from desferrioxamine to deferiprone, on the psychosocial status of a series of thalassaemic patients.

MATERIALS AND METHODS

Forty-four patients were included in this study. They had all been receiving regular blood transfusions and desferrioxamine (Novartis, Basel, Switzerland) chelation therapy (prior to oral chelation), although some patients had thalassaemia intermedia (three patients) or sickle-thalassaemia (three patients). The study was part of a clinical trial to assess the effectiveness of oral chelation using deferiprone (Lipomed, Basel, Switzerland) [5, 6]. There were two groups of patients: group 1 included 34 patients who received only deferiprone (75 mg/kg per day), while group 2 included ten patients who were placed on a combination of deferiprone (75 mg/kg per day) and desferrioxamine (2 g/day sc, twice weekly). Seventeen of the patients from group 1 were initially placed on deferiprone, either because of their poor compliance with desferrioxamine or because of adverse side-effects of the treatment. All other patients were chosen by simple random sampling, from the list of patients treated at the centre, following the random digit table method.

The patients were informed about deferiprone and its potential side-effects, including arthralgias, bone marrow depression, and hepatic changes [1, 7], and all signed a consent form before being started on the new therapy.

The interviews were conducted by social workers familiar with the patients and their parents, working in the department of social services at the Chronic Care Center. Each interview lasted approximately half an hour. For the age group from 12 to 18 years, parents and patients were present at the interview, whereas in the over-18 age group, only patients were interviewed. The interviews comprised simple, direct, open-ended questions and included such information as the name, age, sex, educational level, and profession of each patient, where applicable. Clinical data included the type of thalassaemia, the date of the initial diagnosis, and the beginning of therapy.