

Diabetes in Childhood: Are the Laws Obligations or Resources? The Italian Situation

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Abstract. Two fundamental acts: "Provisions for the prevention and the cure of the diabetes mellitus" of 1987 and "Convention on the rights of the child, New York, 20 November 1989" of 1991, are a clear reference to the many laws promulgated in Italy protecting the special needs of children and adolescents with diabetes. In particular these acknowledge and emphasize the social value of the disease, the importance of the relationship with families and the infrequent need of hospital treatments. To give adequate answers to the need of self-management, it is essential to involve an integrated multidisciplinary team, adequately formed in order to supply an educational therapeutic intervention, based on medical aid and oriented on psycho pedagogy and social assistance. Cooperation and integration among health services of the territory, hospitals and social services for the complete protection of patients with diabetes - not only of their disease - are therefore necessary. Adequate laws can perhaps influence the quality of treatment and the quality of life in children with diabetes.

Key words: Diabetes, childhood, laws

Introduction

A wide literature about the special needs of people affected by diabetes, especially in developmental age, is spread all over the world. But there is not a suitable availability of specific laws safeguarding such needs. In Italy, where there is a long tradition of social security guaranteed by the State, a vast legislative production, protecting both diabetics and children, exists. These laws, if suitably applied, represent a possible answer to these fundamental needs.

Material and Methods

In 1992 the ISPAD Task Force (1) International Declaration g underlined the importance of the relationship environment in children and adolescents, admitting that young diabetics and their families have

both medical and psychosocial needs. The Hvidovre Study (2) investigating on the quality of life in diabetic adolescents, examines the role of families. Family structure, communication procedures and medical treatments of chronic patients are at the centre of a recent interesting report (3). The available literature consistently points out the importance of relationships and of psychosocial factors within the quality of treatments as well as the necessity of protecting with appropriate laws the rights of young diabetics within their relationship environment (4, 5). A close examination of European and American legislation points out the lack of laws actually considering the social character of diabetes. The situation changes in each Country, even where there are similar cultural, economic and social conditions. Most acts are limited to the insurance coverage of medical charges. In some American States there is actually no law referring to diabetes. Therefore we have examined Italian legislation.

Results

In Italy the situation is very different: diabetes is recognized as a disease of great social interest by a state act (6) which takes into account the specificity of diabetic children, creating in every region, paediatric diabetology services directed by a paediatrician. This act sets the objective of self-management as the final goal of every enterprise involved in diabetology field related to the whole population with the co-operation of the social sanitary services of the territory; therefore we go beyond self-control which itself already represents an achievement for the house monitoring of the therapy. By now, it is well known that the self-management of the pathology, acquired through a careful and consistent work on health education, is the most effective method to reach a good metabolic compensation. This slows down the development of organ complications that are the cause of the deterioration of quality of life and of lifespan shortening in diabetic patients. Diabetic patients seldom need ordinary hospitalisation but it is very important to create a counterpart in diabetics' everyday life. We can reach this goal only by means of a better organization of diabetology services or of a wider integration between the many structures and professionalism existing in the territory, from generic doctors to family paediatricians. Therefore we need to continue creating opportunities focused on giving a better quality of life to patients and their families as well developing their possibility to take part in social life. Not hospitalizing does not mean removing children from hospitals, decreasing economic resources, but removing hospitals from children in order to humanize treatments. Not hospitalizing children requires the integration of the specialist's competences existing in the sanitary structures of the territory, in schools and in the other structures involved in medical care of people affected by chronic diseases in developmental age (8, 9). Working in "out-patients" departments or in day hospitals in an interdisciplinary system aimed at the prevention, early diagnosis, treatments, prevention of complications, health education of patients and of the whole population, we can guarantee to diabetic patients in developmental age, a complete, constant and qualified range of services. Keeping reservations in hospitals in cases

of the onset of the disease or in metabolic emergencies, we can avoid psychological problems on which future attitude towards one's own diabetes depends on. The co-ordination of interventions, from the point of view of the different sectors involved in the production of social sanitary services, is indispensable as well as urging institutional co-operations, from a district dimension (10), to integrated home health care and providing the other operators with vocational training in specialized centres. In the event of hospitalization, diabetic patients in developmental age have to be treated by a coordinated trained staff, (11) according to agreed and shared protocols studied for the different age groups by scientific companies that guarantee early and protected discharge and that subsequently take care of the discharged patient.

Discussion

An educational therapeutic intervention with such goals, not only provides medical cares but also psychoeducational assistance which is indispensable for the treatment of children and adolescents with diabetes, including insulin therapy, a balanced diet and physical activity. These are the therapeutic instruments essential for the management of diabetes and indispensable for the achievement of a good metabolic control; also these avoid children with diabetes being treated like sick people, or being perceived like diabetics and not like children. We need to go beyond our old clinical approach of diagnosis and therapy mainly pharmacologically-based, and turn our attention towards prevention themes and psychoeducational interventions. The involvement of an integrated multi-disciplinary team (diabetologist paediatrician, nurse, dietician, psychologist, psychoeducationalist, social worker, visitors) is necessary. The spirit of the Italian law is to create a cultural revolution as far as the chronic disease in developmental age is concerned, turning the attention to prevention themes through health education carried out by traditional sanitary environments. By means of a project of programmed, systematic and educating intervention, focused on reaching not only diabetic patients but their whole relationship environment as well, we can obtain an ac-

tive management of diabetes, also providing useful and rational instruments that make them feel 'less sick' and limiting the difficulties they will meet in everyday life, in social relationships, at school, or during sport activities. The intervention of psychosocial operators will be crucial. It will support children during their development age, keeping their diabetic issue on one side. Diabetes must not be denied but it must be considered in its real dimension, just like a problem that can be faced leading a normal life as well. People often think laws are strict rules they have to follow; on the contrary, they are tools to be used, since they respond to the needs of citizens and guide their behaviour. These considerations lead us to a final question: can favourable laws influence the quality of treatment and the quality of life in children and adolescents with diabetes?

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