

Organization of Paediatric Diabetes Units in Italy

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Abstract. Aim of this work is to give a realistic picture of the medical care situation in Italy and to verify its congruence with ISPAD and SIEDP guidelines and the law. In Italy diabetes is recognized as a disease of great social interest by a state act. Sixteen years after its approval, all of the Italian Regions have received the law n. 115/87 with the different acts. Nearly all regional acts provide for both the institution of specialized centres of paediatric diabetology and their individuation at local level. In Italy diabetological paediatric care is well distributed all over the national territory. Activities are operating in almost every region. Actually a lot of paediatric diabetology activities have no formal recognition and no operating autonomy and sometimes the person in charge of the activity is not a diabetologist paediatrician. In spite of what stated by ISPAD and SIEDP guidelines, this is the real situation. Perhaps in the future a larger presence of scientific societies involved in problems concerning sanitary politics about diabetes, will bring to an appreciable improvement of the quality of care system of paediatric diabetology. (www.actabiomedica.it)

Key words: Childhood, diabetes, organization, guidelines, law

Introduction

Children and adolescents affected by chronic diseases have special needs, regarding their physical, psychical, relational and social sphere. As far as diabetes is concerned these needs have been interpreted by scientific societies that have fixed some clinician-organizational guidelines.

In Italy a special law for the protection of people with diabetes has existed for years. It provides for particular attention to children and fixes the organizational parameters of the services on the territory. Aim of this work is to monitor the medical care situation in Italy and to verify its congruence with the guidelines and the law.

Materials and methods

In order to understand what the needs of children and adolescents with diabetes are and how, we think,

they can be satisfied in Italy, we have focused our attention on the guidelines provided for by scientific societies and the Italian law.

The ISPAD (International Society for Paediatric and Adolescent Diabetes) Consensus Guidelines (1), in its part dedicated to Diabetes Care Organization, reports that medical care should cover the whole territory according to a three or four level model and to population density or incidence of juvenile diabetes:

1. Regional Centers, where it is possible to carry out annual controls in an optimal way. These Centers have also to train other health professionals on the territory and the families, in order to develop self-management abilities of children within and outside the family.
2. District Centers, wide-spread all over the territory according to geographic requirements.
3. Satellite services, organized by Regional Centers, when it is difficult for the children and their families to reach Regional Centres.

4. Where there is a small number of children with diabetes, the management can be entrusted to a paediatrician or to a general practitioner at local level. These professionals should be adequately trained by the team of the Regional Center, that should guarantee an easy access to consultations.

The organization of the diabetes care team, its size and situation will depend on geographical and demographic characteristics, but it must however assure a multidisciplinary participation of some essential members such as paediatricians specialized in diabetes/endocrinology, diabetes specialist nurses and/or diabetes educators, dieticians. Other health care professionals should be part of the specialist team, or at least there should be easy access to psychologists, psychiatrist counsellors, social workers, chiropodist podiatrists, trained in paediatrics and specialized in childhood diabetes.

According to the ISPAD, the centers of paediatric diabetology must assure specialized hospital medical care, preferably in outpatients' department and out of clinic activities, as the organization of local (and national) support groups, resources, nutritional games, experiments, innovations, discussion groups, activity days, visits, lectures, holidays, camps.

But in Italy, a special act "Provisions for the prevention and the cure of diabetes mellitus" has existed since 1987 (2). Before ISPAD Consensus Guidelines, it provided for a similar territorial organization of diabetology care system, articulated into three levels, paediatrician included, and entrusted similar tasks to Paediatric Diabetes Units. Moreover the Diabetes Unit should collaborate with the Local Health Units for all the problems regarding health politics about diabetes. A successive bill "Plan of action in prevention and cure of diabetes mellitus" (3) provided that the staff of paediatric diabetologic units was such as to guarantee the full functionality of clinical activity and home care. The staff included paediatrician, psychologist, nurse, dietician, social worker and home care nurse.

In 2003 also the SIEDP (Italian Society for Paediatric Endocrinology and Diabetology) elaborated the clinician-organizational guidelines for diabetes in developmental age, according to ISPAD guidelines and the Italian laws. Also SIEDP guidelines (4) plan

a care model articulated into three levels, in the respect of the National Health Service and the geographic situation:

1. Family doctor (Paediatrician or General Practitioner) (1st level).
2. Paediatric Units (2nd level): Specialistic Paediatric Units of Diabetology (SPUD) within Operative Paediatric Units.
3. Regional Units for Paediatric Diabetes (RUPD) (3rd level).

Performances, preferably out-patient, within and outside the structure, are assured by a multidisciplinary team with specific training.

In order to verify the degree of adherence of the organizational situation of paediatric diabetic structures to the guidelines and the law in Italy, we have compared the results of a SIEDP national study carried out by Maurizio Vanelli in 2000, (5) with those of an analogous study that we carried out in 2003 (6). In both cases we used data acquisition cards sent to all those attending the SIEDP Study Group on Diabetes.

Results

In Italy diabetes is considered as a disease of great social interest by a state act (2) which recognizes the specificity of diabetic children by instituting paediatric diabetology services directed by a paediatrician, in each region.

In 2000, 52 cards were sent (Fig. 1) to diabetologist paediatricians enrolled to the SIEDP Study Group on Diabetes and 32 centers answered (61%). Most of these had a formal recognition from the Re-

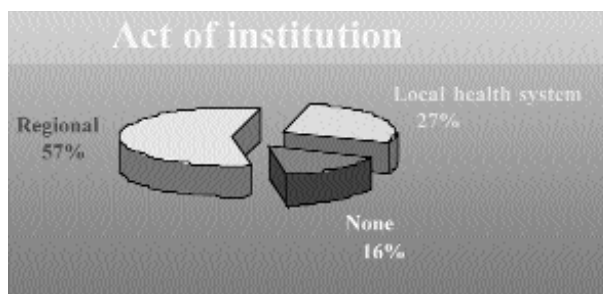


Figure 1. National Survey on activity of Paediatric Diabetology (December 2000)

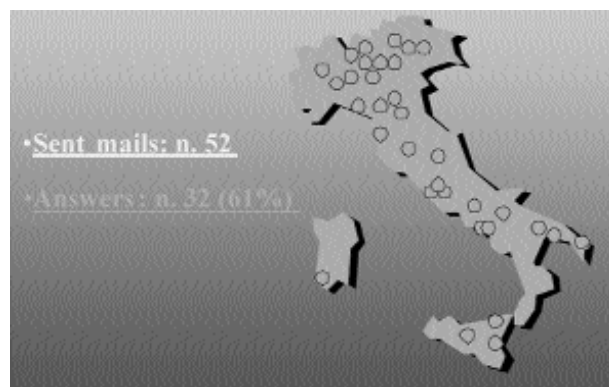


Figure 2. National Survey on activity of Paediatric Diabetology (December 2000)

gion (57%) or the Health Service they belonged to (27%), while 16% of the centers had no formal recognition (Fig. 2).

With the 2003 questionnaire we intended to verify if in the last three years something in the application of the law and of ISPAD guidelines has changed. Therefore we asked the members of the Study Group some more specific questions about the local situation where the centers operate; this, with reference to the recent SIEDP clinician-organizational guidelines as well. The questionnaire was sent to 53 centres enrolled in the Group of Study and all of them answered (Table 1). Sixteen years after its approval, all of the Italian Regions have received the law n. 115/87 with different acts (Table 2). Nearly all the regional acts provide for both the institution of specialized centres of paediatric diabetology (Table 3) and their individuation at local level (83%) (Table 4).

But do the centres, even if they have been individuated by the Regions, exist formally or virtually? Actually 43% of the activities of paediatric diabetology are working without a formal act of institution, that is, they do not exist as operative units in the organization chart of their health authorities and sometimes the person in charge of the activity is not a diabetologist paediatrician.

Discussion

According to the ISPAD and the SIEDP the involvement of an integrated multidisciplinary team

Table 1. Situation in Italy after the law 155/87 was approved

			N. schede
North (24)	1 Val D'Aosta	Aosta	1
		2 Piemonte	Torino
		Novara	
		Vercelli	
		Alessandria	
	3 Liguria	Genova	1
		4 Lombardia	Milano
		Pavia	
		Treviglio	
		Tradate	
		Brescia	
		Varese	
	5 Alto Adige	Bolzano	1
6 Trentino		Trento	1
7 Veneto	Verona	5	
	Treviso		
	Padova		
	Camposampiero		
	Feltre		
8 Emilia Rom.	Bologna	5	
	Parma		
	Cesena		
	Ferrara		
	Rimini		
Centre (13)	9 Toscana	Firenze	5
		Pisa	
		Lucca	
		Grosseto	
		Arezzo	
	10 Umbria	Perugia (Terni)	1
	11 Marche	Ancona	1
	12 Lazio	Roma (Sapienza)	6
		Roma (Tor. Verg.)	
		Roma (Gemelli)	
		Roma (OBG)	
		Roma (Palidoro)	
	Viterbo		
South (8)	13 Abruzzo	Chieti	1
		14 Molise	Campobasso
	15 Puglia	Bari (Giov. XXIII)	4
		Bari (Policlinico)	
		Brindisi	
		Tricase (LE)	
16 Campania	Napoli (II Univ.)	2	
	Napoli (Univ. Fed. II)		
Islands (8)	17 Sardegna	Olbia	4
		Cagliari (Brotzu)	
		Cagliari (Cl. Ped.)	
		Sassari	
18 Sicilia	Caltanissetta	4	
	Catania		
	Messina		
	Palermo		

Table 2. Regions where the law 115/87 was applied

	No	Regional Act	Regional Sanitary Plan	Other
North		Val d'Aosta Piemonte Lombardia Emilia Rom.	Trentino Emilia Rom.	Veneto Bolzano (delib. Giunta Reg.)
Centre		Toscana Marche	Toscana Umbria	Lazio Umbria (delib. Giunta Reg.)
South		Abruzzo Molise	Molise Campania	Puglia (delib. Giunta Reg.)
Islands			Sardegna Sicilia	Sicilia (decr. Assessor.)
Total	9		8	6

Table 3. Do the regional acts include the institution of specialized centres?

	Si	No
North	Piemonte Liguria Lombardia Bolzano Trentino Veneto Emilia Romagna	Val d'Aosta
Centre	Toscana Marche Lazio Umbria	
South	Abruzzo Molise Campania Puglia	
Islands	Sardegna Sicilia	
Total		

(diabetologist paediatrician, nurse, dietician, psychologist, psycho educationist, social worker, visitress) is necessary. The spirit of the Italian law is to lead a cultural revolution as far as chronic disease in developmental age is concerned, turning the attention to prevention themes through health education carried out by traditional sanitary environments.

In Italy diabetological paediatric care is well distributed all over the national territory. Activities recognized by the SIEDP are operating in almost every region. Considering that all the people who received the questionnaire answered, we can underline that the SIEDP has stirred up the experts' interest in the organizational problems. Even if experts are forced by both the need to assure cares of quality and the structural lacks deriving from the missed application of the laws and the guidelines. In the last years the SIEDP has operated a constant pressure on the Ministry of Health to apply the diabetes act. Perhaps, this has caused a positive effect at regional level as well. The National Sanitary Plan and all the Regional Sanitary Plans dedicate a specific part to diabetes and turn particular attention to cronicity in developmental age. Nearly every Region provides for the institution of the centres deliberated by the 1987 act and most of them individuate the Health Services or the Paediatric Departments where the Reference Centres can be settled. Therefore we can say Regions performed their tasks, by carrying out the organization deliberated by the State law and the guidelines. But this is in contrast with the fact that about half the activities of paediatric diabetology working in Italy, some of them very important, do not have any formal act of institution yet, 16 years after the approval of the act n. 115/87. Actually they are working, but they are not recognized as operating units, so they have no operating autonomy. This means that they cannot have qualified staff available and in conclusion, that they have got limited resources. Really these factors stop the supply of the sanitary services provided for in the guidelines and therefore lead to an unsatisfactory and dissimilar quality of care for all diabetic children.

Conclusions

Sixteen years after the approval of the act n. 115/87, in Italy a lot of paediatric diabetology activities have no formal recognition and no operating autonomy. They do not have a qualified staff at their disposal and therefore they are not able to offer all the social sanitary services provided for in the act, inside and outside the hospital. All of that is real, in spite of

ISPAD and SIEDP guidelines. Why do not many centres (even very important) have any institutional act yet, 16 years after the act n. 115/87? Who is responsible for controlling the application of the act and of a qualitatively regular service for all patients ?

Local Sanitary Hospital Services having economic autonomy do not often think about investing in paediatric diabetes structures.

In conclusion, are unapplied guidelines useful? Do we all really think it is useful to apply guidelines? These questions, apparently provoking, lead us to think about the role of the Scientific Societies in Sanitary Organization.

In the last years the careful work of SIEDP, in this way, has produced some positive results.

Perhaps in the future a larger presence, at regional level, as well as at national level, of scientific societies involved in problems concerning sanitary politics about diabetes, will bring to an appreciable improvement of the quality of cares in paediatric diabetes.

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