

Effectiveness of a tailored medical support to overcome the barriers to education, treatment and good metabolic control in children with type-1 diabetes from ethnic minorities

Brunella Iovane¹, Antonina Marta Cangelosi², Ilaria Bonaccini², Carla Mastrorilli³, Dora Di Mauro², Valentina Fainardi³, Giovanni Chiari¹, Marilena Maltese², Carlo Caffarelli², Maurizio Vanelli⁴

¹Regional Diabetes Center for children; ²Postgraduate School of Pediatrics; ³Research Doctorate in Medical Science; ⁴Centre on health systems organization, quality and sustainability, Children Hospital and University of Parma, Parma, Italy

Summary. *Aim:* To analyze the effectiveness of a tailored medical support to help children from ethnic minorities to achieve the same good metabolic control of autochthonous peers with type-1 diabetes (T1D). *Methods:* Children <10 years of age belonging to ethnic minority (EM) families (Group 1) were compared with autochthonous peers (Group 2) who received the diagnosis of T1D in 2014–2016. The Protocol for minorities included other than the standard protocol: booklets translated in ethnic minority languages; weekly visits at home or at school; family-guides; clinic visits supported by professional interpreters. After twelve months of this approach, parents of ethnic minority children answered a short questionnaire concerning satisfaction about educational tools for diabetes management. *Results:* From 1st January 2014 to December 31st 2016, 72 children received the diagnosis of T1D at the University Children Hospital of Parma, Italy. Nineteen children belonged to an EM family (26.38%), and were included in the Group 1. Twenty-one autochthonous peers were randomly recruited for the Group 2. T1D was diagnosed at the same mean age in Group 1 (5.2±2.2) and in Group 2 patients (5.7±2.4). Metabolic derangements at diagnosis were more severe in Group 1 than in Group 2 patients. However, patients of both Groups showed a similar decrease in HbA1c levels during the first 3 and 6 months post diagnosis. Patients did not differ in mean insulin doses at discharge and at follow up. The calls to the emergency toll-free telephone number were more numerous from the parents from Group 1 than from the parents of Group 2. Total cost to implement the tailored protocol in Group 1 was higher of 87% compared with the standard protocol used for Group 2 patients. Great majority of parents reported to be satisfied with the provided diabetes education program. *Conclusions:* The results of this study suggested that children from EM families can achieve the same good metabolic control of autochthonous peers with T1D, providing a cost-effective tailored support to their family members. (www.actabiomedica.it)

Key words: ethnic minorities, T1D in ethnic minority children, type-1 diabetes, diabetes costs, home care, telephone care, metabolic control

Introduction

Children from ethnic minorities (EM) with type 1 diabetes (T1D) tend to have poorer glycemic control and more frequent hospital admissions for acute decompensations, compared with autochthonous patients

(1–4). In 2012 we investigated the barriers affecting their chances to achieve the same metabolic targets of autochthonous peers with T1D (5), and we found several difficulties concerning educational and economic deficiencies, and a major need for interpreters (5). Similar observations were reported in Denmark too (6).

Based these data and with the aim of improving the opportunities to overcome the barriers to a good metabolic control we have provided since 2014 a tailored support for newly diagnosed EM patients and family members followed at our diabetes unit. Herein we analyzed the effectiveness of this supplementary medical approach to the standard treatment.

Patients and methods

The study was restricted to children <10 years of age belonging to EM families (Group 1) who received the diagnosis of T1D between 1st January 2014 and 31st December 2016 at the Children Hospital of University of Parma, Parma, Italy. These patients were compared with autochthonous children of same age who developed T1D in the same study period (Group 2). Group 2 patients were randomly selected and were used as control group. Group 1 children were born in Italy from migrant parents coming from a country outside Europe.

Data for this study were collected from medical files of each patient and included: current age, gender, ethnicity, age at diabetes onset, glycated hemoglobin (HbA1c), diabetes ketoacidosis (DKA) severity degree at diagnosis, insulin therapy, annual number of outpatient clinic visits, number of admissions for acute decompensation, treatment cost.

At post diagnosis discharge from hospital, an integrated package of care was offered by a multidisciplinary team to parents and patients of both Groups. The team consisted of pediatric diabetologists, diabetes specialist nurses, dieticians, psychologists. Repeated educational advices on diabetes management, hypoglycemic episodes and DKA prevention were provided. Sticks for capillary blood glucose determination, urine glucose assay, insulin and syringes were free distributed. An emergency toll-free telephone number was also provided (7). The patients were routinely followed in outpatient clinic regimen four times per year.

This standard protocol was integrated for Group 1 patients only with a tailored support including: booklets translated in the ethnic minority languages to help parents to better understand the diabetes management rules; weekly visits of a nurse or a social worker at

home or at school to support parents and teachers in doing insulin injection and monitoring blood glucose; a continuous home care by a family-guide belonging to the same ethnicity; clinic visits supported by an interpreter during the first 6 months.

To involve as many people as possible to this tailored protocol a free available App named “Kids and Teens Diabetes” for mobile devices was created in fifteen languages on 2014 by one of the author (M.V.) to give children, adolescents, parents, teachers, pediatricians and nurses an additional help in managing T1D at school, at work, during exercising or traveling or driving or partying.

After twelve months of this approach, parents of EM children were invited to answer a short questionnaire concerning satisfaction about educational tools for diabetes management. The questionnaire was given by interpreters who were stressed to translate and not interpret the answers of the parents.

DKA at diabetes diagnosis was classified regarding to acidosis severity as mild with venous pH<7.3 or bicarbonate <15 mmol/L; moderate with pH<7.2, bicarbonate <10 mmol/L; and severe with pH<7.1, bicarbonate <5 mmol/L. No DKA status was defined as a metabolic condition characterized by venous pH>7.3 or bicarbonate >15 mmol/L and blood glucose >200 mg/dl, without ketonemia and ketonuria. 3-beta-hydroxybutyrate (3HB) serum levels were tested on a fingerstick blood specimen by a simple-to-use handheld device (Medisens Optium Xceed, Abbott Laboratories, Bedford, MA, USA). 3HB serum levels <0.5 mmol/dl were defined as normal; levels exceeding 1 mmol/dl were retained as hyperketonemia or ketosis; and levels over 3.0 mmol/dl were classified as ketoacidosis (8). Glycated hemoglobin was assayed in outpatient clinic by Bayer DCA-2000 system (upper limit of normal value: 6.0%) (9).

Medical costs for treatment in both groups were estimated from current (December 2016) Parma's University Hospital inpatient price lists.

Statistical analysis

Data were summarized as numbers (n) and frequencies (%) if they were categorical and as mean and

standard deviation (SD) if quantitative. If the data were normally distributed a two-tailed unpaired T-test or otherwise a non-parametric Mann-Whitney U-Test was applied to compare results between groups. Chi-square test (χ^2) or Fisher exact test was used to compare frequencies between groups. A p value <0.05 was considered statistically significant. Statistical analyses were performed with IBM SPSS Statistics for Windows, Version 21.0.

The families were orally informed about the study, using a professional interpreter, when necessary. It was particularly stressed that participation was voluntary and that all data would be treated anonymously. No conflict of interest exists in relation to the subject matter of present paper.

Results

From 1st January 2014 to December 31st 2016, 72 children received the diagnosis of T1D at the University Children Hospital of Parma, Italy. Nineteen of them belonged to an EM family (26.38%), and were included in the Group 1. Twenty-one autochthonous peers who became diabetic in the study period of time were randomly recruited for the Group 2. Their characteristics at T1D diagnosis were summarized in Table 1.

T1D was diagnosed at the same mean age in Group 1 (5.2±2.2; range 2-8 years) and in Group 2 patients (5.7±2.4; range 3.2-9 years; t=0.67; p=0.50).

Metabolic derangements at diagnosis was more severe in Group 1 than in Group 2 patients (Table 1).

Group 1 and 2 children were treated with the same basal-bolus regimen. Mean insulin dose requirement at discharge (0.7±0.2 vs 0.6±0.3 IU/kg), at three (0.6±0.2 vs 0.5±0.2 IU/kg) and at six months (0.7±0.3 vs 0.6±0.2 IU/kg) post diagnosis was similar in both Groups (Table 1).

Families of Group 1 were from India, Morocco, Romania, and Tunisia (Figure 1). Parents were resident in Italy from 2 to 8 years, none of them was affected by T1D. Parents of Group 1 had a school and professional education degree lower than the parents of Group 2 patients. While in autochthonous families middle class professions were equally distributed, in minority families low social levels were prevalent.

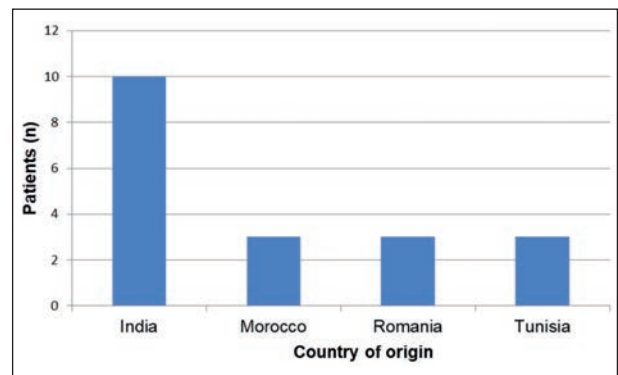


Figure 1. Countries of origin among patients included in Group 1

Table 1. Characteristics of the study population at recruitment

Patients	Group 1	Group 2	p
Number	19	21	-
Gender	10 F; 9 M	15 F; 6 M	p=0.367
Age (years)	7.4±1.4	7.8±0.5	p=0.22
Age at T1D onset (years)	5.2±2.2	5.7±2.4	p=0.49
Metabolic derangements at T1D diagnosis			
• Blood Glucose (mg/dl)	470.4±185.2	249.7±165.3	p=0.003
• Bicarbonate (mEq/ml)	12.7±6.9	17.1±5.0	p=0.007
• pH	7.2±0.2	7.3±0.1	p=0.012
• HbA1c (%)	12.2±4.6	8.3±1.7	p=0.0007
• 3HB (mmol/dl)	5.9±1.5	3.7±1.4	p=0.0001
Insulin dose after diagnosis (IU/kg)	0.7±0.2	0.6±0.3	p=0.228

HbA1c

At diagnosis children from Group 1 had a HbA1c mean value significantly higher ($12.23 \pm 4.6\%$) compared with Group 2 control patients (8.26 ± 1.7 ; $t=3.69$, $p=0.0007$) (Table 1). Group 1 and 2 patients experienced a decrease in HbA1c levels during the first 3 months post diagnosis (7.10 ± 0.96 and 7.48 ± 1.06 ; $t=1.18$, $p=0.24$) (Figure 2). HbA1c values appeared to be stabilized over the next 6 months (7.54 ± 1.2 and 7.62 ± 0.87 ; $t=0.24$, $p=0.80$) (Figure 2). The recommended HbA1c level $<8\%$ was maintained by 76.20 and 78.90 % of Group 1 and 2 patients respectively ($\chi^2=0.04$, $p=0.83$) during follow up.

Compliance

The calls to the emergency toll-free telephone number were more numerous (mean 2.5 calls/week/patient) from the parents from Group 1 than from the parents of Group 2 (mean 0.5 calls/week/patient). Eleven parents benefited from access to the App “Kids and teens diabetes”, the others have been forced to renounce because of a not enabled mobile. The most consulted items were: hypoglycemia, intercurrent illnesses, physical activity.

No patient in Group 1 and 2 needed a re-admittance to hospital because of an acute decompensation. The same percentage of patients in Group 1 (22.2%) and 2 (19.9%) missed outpatient visits during follow up.

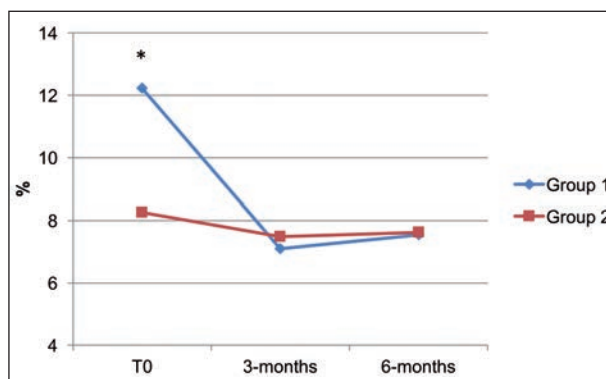


Figure 2. Levels of HbA1c during the period of the study among diabetic children belonging to Group 1 and Group 2. * p value=0.0007

Costs

Hours devoted on average by health professionals to self- control education before discharge were more numerous in Group 1 than in Group 2 patients (18.5 ± 4.5 vs. 6 ± 1.5 hours; $t=10.99$; $p=0.0001$). Weekly visits of a nurse or a social worker at home or at school was provided for Group 1 patients only; on average these occurred with the frequency of 2.5 visits /month/patient in the first trimester post diagnosis, and of 1.5 visits/month/patient in the next months. In 52% of Group 1 children healthcare professionals needed an interpreter to communicate with parents.

Total cost to implement the tailored protocol in Group 1 resulted higher of 87% compared with the standard protocol used for Group 2 patients.

Family questionnaire

Eighteen out of 19 minority parents replied to the questionnaire. Fifteen out 18 parents were satisfied with the provided diabetes education program; only three parents disagreed. Who answered the questionnaire appreciated the distribution of educational booklets in their own language. Ten out of 19 parents agreed the combination with a guide family; nine parents did not share this support because they feared the visits would violate their privacy. All parents on the contrary appreciated the visits of a nurse at home and/or at school, as well as the availability of a direct and free telephone access to the healthcare team.

Limitations

We are aware that the present study has some limitations. At first, the number of participants is small, but it is representative of a local experience. The Authors are convinced that in EM field local investigations more than larger studies are useful to find effective resolutions to barriers to diabetes management. Many of the measures taken with our tailored protocol could not have been implemented in a wider, more populous and heterogeneous area. For example, the promotion of innovative and expensive services, such as the visits at home and school, family-guides

support, interpreters intervention and the printing of educational booklets, has been facilitated by the availability of free resources already exploitable in loco.

A second limitation might be due to the questionnaire administration by interpreters. This procedure could be resulted in misunderstandings during questions presentation and translation. The operators were professional interpreters and were taught to translate and not interpret families' queries and replies. We believe that similar problems would arise if the same parents, given their limited educational background and language difficulties, had answered the questionnaire without the help of an interpreter.

Discussion

The results of this study suggested that it is possible to overcome the barriers that commonly affect the chances of a child with T1D from an EM family to achieve the same good metabolic control of an autochthonous peer. These barriers are generally due to difficulties in understanding healthcare professional messages, in approaching local healthcare system, in coping cultural background with the requirements of a disease that implies a continuous collaboration and application (5, 6). Healthcare professionals have generally limited supports to find appropriate solution to their inadequacy that might result in poor metabolic control in these vulnerable children.

We highlighted this discomfort in a previous study and we concluded, in agreement with other Authors (5, 6), that caregivers must be encouraged to provide tailored support for EM children with T1D and their families including interpreters, longer-term visits, teaching nurses, social workers, booklets in different languages. All these resources were added to the protocol routinely in use in our diabetes center, and it was targeted to EM patients only. Based on the data collected over two years in this study we are able to recognize that our effort has produced the expected results.

At T1D diagnosis, children from EM herein studied showed a more serious metabolic derangement compared with their autochthonous peers. This remark recurs often in literature (5, 6, 13). In Hvidøre Study

Group a similar situation has been also associated with a poor quality of life (14).

Moreover, we observed that poor metabolic condition at diagnosis occurred in combination with elevated HbA1c and 3HB values, and we speculated that this association was indicative of a long latency in T1D diagnosis. A surprising event if considered that a campaign for DKA prevention was in progress for several years in the recruitment area (10-12). Most likely the parents were not involved in this campaign and did not learn that one of the warning symptoms of a diabetes at onset is unusual bed wetting in a child ordinarily dry (10). The causes of this misinformation deserve further investigation in order to find appropriate means to break the isolation in which these disadvantaged populations often live.

Post diagnosis follow up showed a rapid decrease in HbA1c levels in both EM and autochthonous children that reached a nadir at 3 months from T1D onset. This glycemic improvement continues in the following months without differences in both two patient groups. Recommended HbA1c level <8% was indiscriminately achieved in the two-thirds of patients. We believe that these expected results has to be related to the supplementary services we added to the standard protocol routinely reserved for autochthonous patients. All these facilities were centered at involving parents in diabetes management and to offer them the means to obtain a good metabolic control and a normal social life for their children.

In this strategy a crucial role was played by the professional interpreters involved since the first day of disease. With their help it was possible to dialogue with people who did not know the Italian language and were burdened by the anxiety in a disease never known before. The use of these professionals has been valuable both in the outpatient clinic, during home and school visits and in educational booklets translations.

A further service appeared in our experience as effective tool for providing continuous support to young people and their parents in the management of diabetes: it concerned the telephone hotline service in use for long time in our center (15). Through this service, parents have free 24-hour access to an experienced physician or nurse who guides them through the process of managing e.g. an episode of acute decompensa-

tion or during an intercurrent illness. Thanks also to this support, none child from ethnic minorities needed to be re-admitted to hospital.

Among provided services, family-guides did not have unanimous consensus. Some EM families have esteemed these visits as a violation of their privacy or in conflict with their religious background. Future supports in this field should be better calibrated on family cultural, religious and educational background.

We are aware that the protocol applied in this study had an elevated cost exceeding the one routinely reserved to indigenous people, and its implementation has required resources not always available in all centers. We are equally conscious that the major goal of a nurse or a pediatrician involved in diabetes education is to develop in parents and children with T1D the ability to manage a disease that requires a continuous collaboration. This demanding engagement of EM families commonly conflicts with several barriers. It is a duty of a caregiver to know these obstacles and to find the right means to eliminate them. That is what we tried to do in the current study.

The same decrease in HbA1c levels, the same insulin requirement, the same degree of compliance, the lack of hospital admissions herein reported in EM children and autochthonous peers during follow up are convincing evidences that the goal has been attained. Given this benefit, it is reasonable to consider our study as cost-effective.

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Correspondence:

Brunella Iovane, MD

Regional Diabetes Centre for Children

Children Hospital "Pietro Barilla"

University Hospital of Parma

Viale A. Gramsci,14 - 43123 Parma, Italy

E-mail: biovane@ao.pr.it