Outside-hospital assistance for children and adolescents with type 1 diabetes mellitus

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Abstract. Telephone care, Telemedicine, Home care and Diabetic Camps are the most useful ways for Paediatricians to transfer diabetic care outside the hospital. These provide children with diabetes and their parents with an effective and practical tool to solve directly arising therapeutic problems and improve their quality of care and life. The advantages for the National Health Care System could be macroscopic: according to some studies, the Telephone care service allows to save 85% of the hospitalisation costs for children with acute metabolic intercurrent illnesses-related derangements. Telemedicine service, based on telephone line relying on the internet technology, is a complementary tool to follow children and adolescents with diabetes in out-patient clinic. The rare experiences in this field report a reduction in insulin doses and an improvement of metabolic control and quality of life. The Home care service has to be performed by a nurse and has to be useful for patients and parents to organize the management of diabetes at home and to improve therapeutic adherence. Diabetic camps give the opportunity to children and adolescents with diabetes to verify, outside the family and under health professionals' supervision, their ability to manage the disease, and to increase own self-esteem. (www.actabiomedica.it)

Key words: Type 1 diabetes mellitus, home care, telephone care, diabetes camps, telemedicine

Type 1 Diabetes Mellitus (T1DM) results in the complete disorder of carbohydrate metabolism caused by the lack of insulin. Daily medication regimens, insulin injections and blood glucose monitoring are a complex and uncomfortable management. To be successful, children and adolescents with T1DM require continuous medical care and education to prevent acute complications, to reduce the risk of long-term complications and to improve their quality of life (1). Diabetes care is provided in a wide variety of settings in and outside the hospital.

Periodical medical controls in outpatient clinics should not only be addressed to check and maintain the re-established metabolic equilibrium, but should also lay the basis for a quality of life that is as close as possible to that of non-diabetic peers (2). In order to obtain this goal, educational programs tailored to the patient's learning resources and supported by video clips, animations, pictures and booklets are generally used by the health professionals (3). Despite these efforts, young people with T1DM and their parents once at home, school or work, continue to report some difficulties in putting into practice the teaching they received in the hospital.

In this scenario, the outside-hospital assistance (OHA) should be promoted at three different levels: where the patient lives (home), where he/she spends most of his/her daily life (school), where he/she eventually works. Besides these three forms of OHA, a fourth one may be added: summer diabetic camps, devoted to promote autonomy from the parents in the management of T1DM.

In order to reach home, school and the work places, *Telephone care and Home care* services as OHA ser-

vices have been originally organized *(4,5)*. *Telemedicine* is a more recent experimental OHA service, nowadays only used in few diabetes centres (6).

An update of these OHA services for young people with T1DM is herein proposed with particular reference to the experience made at the Interuniversity and Regional Centre of Paediatric Diabetology of the University of Parma which is considered a pioneer Centre in this field both in Italy and in Europe.

Telephone care

Telephone is today the quickest means for communication between patient and physician. It is common knowledge that the first phone medical consultation was made in 1876 by A.G. Bell, inventor of the telephone, who called his doctor after pouring sulphuric acid on himself, obtaining in real time all supports for treating his injuries (7). From then on, the use of telephone for consulting became more and more popular reaching its peak in the 60's and 70's.

In Medline more than 20 thousands articles on this subject are presently available, but only 30% refer to paediatric experiences. The search by the key word "Diabetes" produces a very low percentage of citations (0.6 %) compared to other matters. As far as it concerns children with T1DM the citations are merely anecdotal (8).

The best known telephone care patterns are three: *Mini switchboard system* (the telephone operator connects the calls to the specialist required), *the follow on system* (the call arrives to a telephone exchange and is automatically connected to the first available free line) and the *Multitier system* (the calls are handled directly by the trained staff and specialists are involved only occasionally) (4).

In several Children Hospitals, abroad, hot lines work 24 hours for chronic patients. In Italy, these facilities continue to be uncommon, due to the costs, so that only few patients take advantage from these supports today. All effective hot lines should present 3 requirements: autonomous line, free access and trained staff, but it is difficult to guarantee these conditions in the Italian health system which is centred on savings and restrained investments.

In Parma, Italy, we solved this problem by involving the parents' association of children with T1DM which accepted to finance both a toll-free telephone number (800.848043) and an experienced staff in T1DM management selected among the fellows of the Post-graduate School of Paediatrics of the University of Parma and the nurses of the local Regional Centre of Paediatric diabetology.

The Parma Telephone care pattern differs from those previously mentioned and could be defined as a *Direct system* since the users are immediately connected to a selected Fellow, Nurse, Paediatrician or Dietician experienced in the management of T1DM. This Telephone care provides a 24 hour service for 7 days a week. From 8 am to 6 pm the calls are answered directly by the staff operating in the Centre of Diabetology and during the following 14 hours by the fellows on duty who answer the different questions using written guide-lines and an on-line manual.

Telephone care also involves a detailed preparation of the operators which are selected among the most motivated health professionals with self-control, able to answer clearly and shortly, and who can always reply according to what the patients and parents have learned during the stay in the hospital and at the outpatient clinic.

In 5 years of Parma Telephone care activity, 9.125 calls (an average of 5.1 a day) were received. Only 24% were defined as veritable emergency hot line calls. The real hot line calls were 765 and 59% of them came from the region where the Parma centre is operating. The users had a mean age of 7.8 ±4.3 years and an average duration of diabetes of 2.8 ± 1.2 years .

Eighty-nine percent of the calls referred to intercurrent illnesses. Under this point of view we obtained a remarkable goal. The hospitalisation of young people with T1DM due to an acute intercurrent illness decreased by 85% during 5 years of activity. Compared to the previous period without Telephone care, 213.000,00 € were saved on hospitalisation costs. The saving appears even greater if compared with 6.000,00 € paid by the Parma Youths of Diabetes Association for the calls arrived to the free-toll telephone number in 5 years.

The Parma hot line, originally conceived for helping children with DMT1 and their families faced

with a diabetes-related emergencies, also gave a decisive contribution to the success of the prevention campaign against Ketoacidosis at diabetes onset promoted in the province of Parma at the end of the 90's in schools, families and General Paediatricians (9).

Home care

In those countries where Home care has been promoted, an improvement in the quality of treatment and life, and a drastic decrease in hospitalization have been reported (10-12). A short but well structured hospitalization, followed by a Home Care service (HCS), has been shown to be more effective than a long stay in hospital. Completing the self-management education at home is able to reduce the social cost of the disease (parents don't waste working hours and the same for children at school) and improve patients and their parents' knowledge about diabetes (13). According to these results the International Society for Paediatric and Adolescent Diabetes (ISPAD) decided to stimulate HCS institution where and when possible (14).

HCSs for young people with T1DM are rarely available in Italy, though several Italian Regions are managing to promote them. Our Group has organized, the first in Italy, a HCS devoted to supporting the patients living in the Parma Province not only at home but also at school. Our HCS pattern is based on three operating arms: a nurse, a car and a free access by telephone to the health professionals working in hospital.

In order to carry out this service at home we employed a nurse instead of a physician, first of all, because the physician trends to stress medical information more than practical management of diabetes ; moreover he generally speaks using a professional language which is often too difficult to understand by the patients and their parents. Secondly because the aim of a HCS is not to bring the hospital at home, but to transfer outside the hospital all the useful tools to complete and improve the management of diabetes, and to help patients and parents solve the problems at once when these occur. We are convinced that a nurse is the best health professional can carry out this role provided that she is supported by an organisation in the hospital consisting in physicians, psychologists, social workers and dieticians. This goal may obtained by connecting the nurse to the Diabetes centre by a direct phone access. This aim was met in Parma using the toll- free hot line financed by the Association of the parents of children with diabetes as discussed above in this paper.

Time and date for home visit must be previously arranged with parents and teachers. Visit-time preference falls in our experience at the late afternoon when the family joins together after work and school. In patients with peculiar problems these visits should occur every three months. The first meeting with the families aims to debate general aspects on the diabetes management at home (i.e. how to prepare an insulin injection, how to perform the routine tests for diabetes control, availability of materials for hypoglycaemic episodes treatment).

The meeting at school aims to check the presence in class-room of the most common supports for diabetes management (i.e. strips for blood and urine glucose tests, glucose tablets and glucagon vials), and to record an interview to the teachers on their opinions about diabetes. A special meeting has to be reserved with the personnel who manages the school meal in order to explain the diet and to establish the portions.

During the visits at home, the nurse noticed several anomalies in the use of insulin and its keeping, and on performing blood and urine glucose tests and the visits at school highlighted erroneous teachers opinions on diabetes that is considered as a fatal or an infectious disease.

HCS showed to be useful tool in reducimg the parents' distress in takeing on the burden of diabetes management at discharge from the hospital after the diagnosis. The possibility of meeting at a nurse home the same day may give them of leaving the hospital who could help parents manage i.e. the first insulin injection might give a great support in improving confidence in the self-management of diabetes (10, 11).

Summer diabetes camps

The first camp for children with T1DM was opened in 1925 in USA (15). At present they are carried

out all over the world. Summer camps represent a very important moment for children, because their parents leave them alone and they have to learn by themselves all that the professional team teaches them. The aim of diabetes camps is to allow for a camping experience in a safe environment (16). An other important goal is to enable children with T1DM to meet and share their experiences with other children while they learn to be more responsible the management of their disease. In the camp setting, the recreational, educational, social and health care needs of children can be met in a safe, enjoyable and productive environment.

In these camps, groups of young people of the same age live together for 10-15 days with the health professionals from their Diabetes centre who are involved in the management of their disease. These camps also have the aim of showing participants that several sport activities are consistent with diabetes. In a camp the following professional figures are usually present: a paediatrician experienced in diabetes management as camp director, a nurse, a dietician, a psychologist and *animators*. Many children learn during the camp how to inject insulin, how to correctly interpret the symptoms of an incipient hypoglycaemia, how to prevent the lowering of blood glucose levels during physical activity, and how to perform and interpret blood and urine tests.

The diabetes camp is also a place where many taboos can be destroyed, such as eating ice-cream and sweets. Thanks to an interesting experience made in the camps promoted by our group, many of our patients have learned that the consumption of an ice-cream or cake at the end of a meal enriched in vegetables does not produce a post-prandial hyperglycaemia. On the contrary, when the same sweet portions are consumed between breakfast and lunch or between lunch and dinner the effects on the blood glucose levels are devastating (17).

Telemedicine

Telemedicine is a system that relies on internet technology to give assistance outside the hospital, connecting a patient with his/her physician. The first experiences of telemedicine began in the 60's in U.S and Northern Europe, but after the establishment of Internet, information technology dramatically grew (18). In Diabetology, Telemedicine had its origin in the 80's. Initially , patients with diabetes sent only the data concerning the blood glucose monitoring (19). Nowadays, it is an instrument of great support for the patient in organizing the management of diabetes in improving therapeutic adherence and in increasing its self management.

The recent systems of Telemedicine are based on two units : Patient Unit (PU) and Medical Unit (MU) connected to a Telecommunication System (TS) . Following the model used by D'Annunzio et al. at Gaslini Hospital, University of Genova, Italy, PU communicates with MU and it is placed in the patient's house (5) . Moreover PU contains software for storing data of the daily controls. MU is placed in the hospital and is used by a diabetologist . TS is based on Internet technology and telephone lines. MU receives by PU the data on blood glucose concentration, urine glucose and ketone levels, insulin unit, hypoglycaemic episodes indicating the average adherence of the patient's therapy. After receiving all these data MU personalizes a therapy for that patient and sends it to the PU in real time. If the PU does not share these suggestions the patient can dialog with his physician finding the most convenient solution.

The users of Telemedicine are very motivated to reach standard levels of metabolic controls, to follow a diet and to practice physical activities. A satisfactory improvement in metabolic control and a decrease in insulin need are reported (5). In spite of the results, the visits at out patient clinics are decreased, meaning that the patient does not substitute this system with the direct relationship between physician-patient.

Gaslini Hospital pilot experience demonstrated that, even if the cohort of patients enrolled was small, their compliance with telemedicine system was higher than expected, as reported by the high and constant number of links between the PU and the MU. Furthermore patients showed good acceptance of the system and continued to use telemedicine for their disease management. On the other hand, physicians performed more therapeutic protocol adjustments using Telemedicine, demonstrating how telemedicine could help face any undesired metabolic imbalance promptly (5).

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References

1. Santiago JJW, White NH, Pontious SL. Diabetes in childhood and adolescence. In: Alberti KGMM, De Fonzo RA, Keen H, Zinnet P. Eds. International Textbook of Diabetes Mellitus. Chichester: John Wiley & Sons Ltd 1992; 1025-57.
2. American Diabetes Association, Standards of Medical Care in Diabetes–2006, *Diabetes Care* 2006 29: S4-42.
3. Vanelli M, Chiarelli F, Chiari G, Tumini S. Relationship between metabolic control and quality of life in adolescents with type 1 diabetes. *Acta Biomed Ateneo Parmense* 2003; 74; Suppl. 1: 13-17.
4. Chiari G, Ghidini B, Vanelli M. Effectiveness of a toll-free telephone hotline for children and adolscents with Type 1 Diabetes. A 5-year study. *Acta Biomed Ateneo Parmense* 2003; 74; Suppl. 1: 45-48.
5. Tumini S, Anzellotti MT, Chiarelli F. Camps for Children with T1DM. *Acta Biomed Ateneo Parmense 2003*; 74; Suppl. 1: 32-34.
6. d' Annunzio G, Bellazzi R, Larizza C, et al. Telemedicine in the management of young patients with type 1 diabetes mellitus: a follow-up study. *Acta Biomed Ateneo Parmense* 2003; 74; Suppl. 1: 49-55.
7. Car J, Sheikh A. Telephone consultations. *BMJ* 2003; 326: 966-9.
8. Chiari G, Vanelli M. Telephone and Hot lines: a tool delivering clinical care. *Acta Biomed Ateneo Parmense* 2005; 76; Suppl. 3: 75-80.
9. Vanelli M, Chiari G, Ghizzoni L, et al. Effectiveness of a prevention program for diabetic ketoacidosis in children. An 8-year study in schools and private practice. *Diabetes Care* 1999; 1: 7-9.
10. Vanelli M. L'assistenza domiciliare al bambino diabetico. *It J Pediat* 1993; 19: 380-3.
11. Vanelli M. L'assistenza domiciliare al bambino diabetico. Bilancio di un' esperienza pilota in Italia. *It J Pediat* 1992; 18: 275-9.
12. Vanelli M. Il bambino con diabete tra pediatria ospedaliera, pediatria di base e pediatria di comunità. In: Viola P, Benaglia G. eds. *Argomenti di pediatria preventiva e sociale.* Parma, 1993: 37-9.
13. Dougherty GE, Soderstrom L, Schiffini A. An economic evaluation of home care for children with newly diagnosed diabetes. Results from a randomized control trial. *Medical care* 1998; 36: 586-98.
14. Consensus guidelines 2000. ISPAD consensus guidelines for the management of type 1 diabetes mellitus in children and adolescents. Medical Forum international, 3700 AR Zeist, The Netherlands.
15. ADA. Management of diabetes at diabetes camps. *Diabetes Care* 1999; 22: 167-9.
16. Renders CM. Intervention to improve the management of diabetes in primary care, outpatient and community settings. *Diabetes Care* 2001; 24: 1821-33.
17. Vanelli M. L'assistenza extra-ospedaliera al bambino con diabete mellito. *Prospettive in Pediatria* 2005; 35: 67-73.
18. La Porte RE, Akazawa S, Drash S, et al. Diabetes and the internet. *Diabetes Care* 1995; 18: 890-5.
19. Montani S, Bellazzi R, Quaglini S, et al. Metanalysis of the effect of the use of computer-based systems on the metabolic control of patients with diabetes mellitus. *Diabetes Technol Ther* 2001; 3: 347-56.

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