

Perspective

The Insulin, Love and Care Project

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Type 1 diabetes is the most common chronic serious disease in childhood and adolescence in many western countries. Its treatment and care is intensive and very expensive not only in terms of money but also in terms of psychology.

Some 25 years ago, a paper on "insulin, love and care" [1] described and underlined the importance of taking care not only of the insulin therapy itself, but also of the human being (child, adolescent, adult), bringing the concept that a physician must have empathy and not just be a "mechanic" of the body.

Beside a near-physiological substitution of insulin, psychosocial care is crucial for the management of diabetes in children and adolescents. This is in fact well known by every experienced clinician, but very difficult to document scientifically. Traditional methods, useful and necessary in clinical or experimental research, are often rough and irrelevant in the description of complicated and 'soft' psychological phenomena, and statistical methods are of little help to prove whether the feelings of a child are acceptable or not.

After 25 years, the words "insulin, love and care" remain as true as ever before. Many papers have been published about the psychological burden of type 1 diabetes [2-13], but usually in a theoretical but less emotional and empathic way.

Since some years we try to put empathy into our daily practice, try to change the relationship with our patients, and to take care of the 'whole' patient with type 1 diabetes, and not just the more somatic and technical parts of the treatment of diabetes.

In 2003 we arranged a summer camp in Sardinia. For the first time, patients gathered from all over Italy, practicing the 'Insulin, Love and Care' philosophy. The participants received a Welcome letter: "Dear Camp Participants, long time ago diabetes in a child or a teenager was a death sentence. Now we know that on an average you will have many decades of a good life in front of you, and hopefully some of you will be cured from diabetes some time in the future. But until then your life will not be "normal". Although nobody has actually a "normal" life, your life will definitely not be normal. It is not at all normal to take insulin several times per day, to eat at regular

times, to eat certain amounts of food and with a suitable content, to measure blood glucose regularly, etc. No, your life will not be normal, but it will be exciting, happy, long, fantastic ... when you just learn how to live with diabetes. Most periods of your life diabetes will not bother you too much, other periods it will be a heavy burden. But do not give up! Never! Soon you will feel better again. My impression from diabetic children and teenager is that YOU ARE IMPRESSIVE! I like you and admire you! You are worthy prize, encouragement, support!

Have a wonderful camp! I wish I could have participated with you! But most important: Have a long, happy life!

After reading and hearing these words it was a completely new way to act and take care of our patients.

Since then, 12 Insulin, Love and Care Summer Camps have been organised (Sardinia, London, Macugnaga, Elba Isle, Alpe di Siusi, Gressoney and Torre Guaceto 2 times, near Brindisi, Orlando, FL, USA, Castiglione della Pescaia, near Grosseto, Foppolo 2 times, near Bergamo), 10 ILC Junior Weekend for children under 10 years and their families and 6 ILC Senior Weekend for young adults ages 18-25. Since then, we bring into focus what we have to work upon, described in our 'Decalogue'.

The Insulin, Love and Care Project Decalogue (see Figure)

The new way to view diabetes; and above all, building trust between diabetes team and patient.

1. There is no such thing as bad diabetes, just one that is difficult to manage.

Diabetes is not only an enemy to overcome, but can also be a partner, demanding but with whom you have to and can learn to live.

2. Being happy is more important than living a 'normal life'.

Try to face diabetes with a smile. It helps. And while not neglecting diabetes and its treatment, you can do most of what your friends can do.

3. Good self-care is a must.

Gradually with age you should learn to manage your diabetes in



the insulin + love & care project

Figure: The figure represent the Insulin, Love and Care Project logo: the drop is for insulin that patients need to inject every day, the heart is for the love we have to put into our practice and the teddy bear is for the care we owe to our children and teens with diabetes. The logo has been created by Dani Pidermann, father of Jake, teenager with type 1 diabetes.

order to become more responsible and independent.

4. Hiding one's diabetes doesn't do anyone any good.

Diabetes should never be hidden. Talking to others about diabetes helps to accept this condition, and become more relaxed.

5. Knowing that poor control is our common fault makes 'cheating' unnecessary.

It is not only your fault if the treatment result is poor! The team/your collaborators and you have a common responsibility. We rely upon you! Cheating is to give up!

6. Having supportive parents by your side is important.

Your parents must be supportive without being invasive or overly protective.

7. Teachers and educators have an important role.

The people who regularly spend time with you as a child or adolescent should accept you as well as everybody else. You should not need to feel 'different'.

8. The doctor is not just a mechanic for the body.

The doctor and the diabetes team should not only concentrate on the disease, but also care for the person burdened with questions and fears, anguish and hopes.

9. Doing it together is easier than by yourself.

Facing diabetes together with others is much easier. It helps you feel less alone, encourages a dialog with those who share your problem, and helps you to follow the rules imposed by diabetes.

10. To live with diabetes does not mean a "normal life", but a long, exciting, happy life!

Diabetes is something to live with. Do not fight diabetes, but try to learn to live together with diabetes.

Our simple rules might help kids and teenagers around the word to live together (and not against) their diabetes. The Decalogue might help physicians and members of the diabetes teams to see the

person, the human being, and not only good or bad blood sugar readings or haemoglobin A1c. This will not only improve quality of life of many diabetic children and adolescents, and also their parents, but will certainly improve metabolic control and decrease diabetes complications.

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