

## Summer Camps and Quality of Life in Children and Adolescents with Type 1 Diabetes

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**Abstract.** Topics concerning quality of life in children and adolescents with Type 1 Diabetes Mellitus (T1DM) and summer camps, have only recently appeared in the scientific literature. Interest in quality of life in diabetic patients has lately increased. The Hvidore study group has recruited 2000 patients from several countries and has published an important paper whose conclusions suggest that T1DM patients have a better quality of life if they have a good metabolic control. The aim of this paper is to evaluate if summer camps, seen as an educational and therapeutic tool, can improve quality of life by increasing knowledge and self-management capacities. Certainly summer camps help T1DM children and adolescents to understand that they can be on vacations, practice sports, have fun with other children away from home and parents, just like every other child and adolescent. At summer camps T1DM patients become aware of not being the only ones to deal with the problem of diabetes; in addition parents become aware of their child's skills in the disease management and lastly improve the relationship with the medical staff who will have the opportunity of living an extremely important training experience. The more ambitious aim of summer camps, i.e. the gaining of knowledge and self-management skills and improvement in metabolic control, seems difficult to achieve. The limited literature available suggests that it is unlikely that one or more summer camps will contribute to the improvement of metabolic control; nevertheless, it is not easy to make such evaluations with scientific criteria. We think that Italian guidelines for summer camps should help in standardizing the organization and management; in this way it will be probably easier to evaluate the impact of summer camps on the quality of life.

**Key words:** Summer camps, quality of life, type 1 diabetes

### Introduction

Quality of life (QOL) in patients with diabetes is a topic which has not received much attention in the past from neither adult nor paediatric diabetologists. The scientific literature on this topic is very poor, particularly as far as type 1 diabetes (T1DM) is concerned. There are also very few studies on summer camps; it is therefore quite difficult to approach the problem of the impact of summer school on quality of life. However, the Hvidore Study Group paper on quality of life, which has encouraged the project of an

Italian study, has represented our starting point. The study provides a first strong evidence that a good metabolic control is associated to a better quality of life; many of us paediatric diabetologists had this impression but this was confirmed by the Hvidore Study Group paper reporting on methodology on a large population. In our opinion, this paper will be a cornerstone of the studies on QOL, with an impact on the management of diabetes comparable to that of the Diabetes Control and Complications Trial (DCCT) on the relationship between metabolic control and complications of diabetes.

Starting from the conclusions of the Hvidore study, the question is whether summer camps are useful to achieve a better metabolic control and therefore a better QOL.

Summer camps are probably a highly enjoyable setting where diabetic patients are trained for self-management and self-monitoring. Thus, it seems obvious that during summer camps patients gain knowledge which should allow them to improve metabolic control, and consequently improving QOL. Unfortunately this is not so simple; indeed literature, although it is not easy to draw conclusive data, suggests that it is very hard to obtain a stable, long-term improvement of metabolic control through summer camp. We need to understand if summer camps can contribute to a better QOL of T1DM patients, independently from the desirable improvement of metabolic control.

### Aims of summer camps

If summer camps are part of an educational process, especially if we want them to contribute to improve QOL, it is important to define the aims to pursue. The aims of summer camps can be divided in short-term and long-term.

#### *Short-term aims*

Sharing the problem with your fellow-men, although with different attitudes, is one of the most important aspect of summer camps; realizing that you are not the only one with the disease, can be of help in overcoming psychological problems which a chronic condition like diabetes inevitably implies. Going away from the family is a relevant aspect; in fact when a chronic disease is diagnosed, it can cause a number of problems within the family, upsetting psychological balance among family members. Spending one week away from such family pressure, particularly if the parents are reassured by the presence of the medical staff - hopefully the same who usually take care of the child - is for the parents a break to daily worries about the management of the disease and for the child an opportunity to socialize and have fun.

Summer camps can also be and opportunity for the child to prove self-management ability to his or her parents; the parents, reassured by the continuous surveillance on behalf of the medical staff, will realise that the child can be more independent than what they thought. This will help the family to feel more comfortable and confident.

Involving the children in sport activities is another educational aspect of summer camps; both children and families will realize that sport is not only useful to improve metabolic control but it is also important to have a more healthy life, to spend time with fellow-men and to have fun.

As already said, it is important that the summer camp staff is made up by the same people who usually assist the child; confidence and familiarity between the child and the staff will help to face the inevitable moments of distress and anxiety, well known to whom has experienced summer camps.

Attending a summer camp is also a unique work experience for medical staff. This experience will change their perspective of the disease, will generate a greater familiarity with the children and will improve the relationship between physicians and patients.

#### *Long-term aims*

We often think of summer camp as something which could help improve the metabolic control of some of our diabetic children; we also now that a better attitude towards the disease can be achieved increasing knowledge to reach independence and self-management. Such aim should not be considered too ambitious since every book and booklet on diabetes, in the chapter on education, includes the topic of summer camp considering them as one of our tools to reach such achievements. However, in order to make such education effective, diabetic patients should achieve self-management and therefore the desired improvement in metabolic control. The age of the children has a strong influence on the ability to achieve independence and self-management; therefore, the education program needs to be planned taking into consideration the age, as well as the duration of the disease and previous level of education of the participants.

Children and adolescents go back home from the summer camp very happy: they've had fun; they've enjoyed to spend time with other diabetic children, who became their friends, and with their doctors and nurses; they learned to give themselves the insulin injections and to manage planned and unplanned physical activities; in addition they've learned which food to eat to correct hypoglycaemia. Their quality of life has improved as well as their glucose levels. But all this does not last long. Unfortunately, once back at home responsibility and disease treatment pass back to the family, the patients progressively forget what they had learned and glycemic control worsens.

Long-term aims of summer camp, i.e. achievement of disease self-management, are not easily assessable with scientific criteria; the difficulty in drawing scientifically valid conclusions is probably explains the lack of studies on this topic.

## Conclusions

There are few papers on diabetes and quality of life; there are even less regarding summer camps and quality of life. These studies seem to suggest that the metabolic control does not significantly improve after having attended one or more summer camps; therefore the aim of improving QOL of diabetic patients by helping them achieve self-management with summer camps is not an easy task.

The QOL project of the SIEDP study group is extremely important not only to provide a scientific contribution to the topic but also as a starting point to standardize summer camps.

One of the problems in evaluating the role of summer camps with scientific criteria is due to the different categories in which these are divided into: patients, physical activities, teaching activities, etc. Vari-

ability in the way camps are organized depends also on the fact that often they are based on voluntary service. As far as this aspect of summer camps is concerned, the Italian guidelines would be an important tool in order to abandon improvisation and voluntary service in summer camps for T1DM patients.

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