

Type I diabetes therapeutic education in a non-governmental association T1 diams: an overview

Abstract

Background: Type 1 diabetes is a chronic endocrine disease requiring a lifelong insulin treatment. T1 Diams, a Mauritian non-profit organisation specialised in the care and self-management of Type 1 Diabetes in Mauritius, has been working on the development and implementation of therapeutic and educational activities, during the last 10 years. The aim of the study is to give an insight of their therapeutic educational program.

Methods: This retrospective study was carried out from March- April 2015. The author was given a contract of consultancy where he evaluated all the therapeutic educations carried out by T1 Diams.

Results: Therapeutic education is carried out by two diabetes educators and a general practitioner. The first stage consists of doing a diagnostic questionnaire to evaluate the present knowledge (pertaining to Type 1 diabetes) for each member. 6 themes (What is Type 1 diabetes, Hypoglycaemia, Hyperglycaemia, Insulin/Adaptation, Nutrition and Personal experience) have been identified. Educational games and presentation have been devised on these themes. The whole program is based on empowering the Type 1 diabetic patient with this knowledge, which is of utmost importance, for the management of their medical condition. There was a minimum total of 90 visits per month for ongoing home and centre visits carried out by the diabetes educators, 12 therapeutic educational group sessions as recreational diabetic day (Enjoy Life and T1 Diams en ballade) and a one week-long annual diabetic camp are carried out for the whole year. Every 3 months T1 Diams releases a news bulletin on diabetes education for the public. Furthermore the association organises once a year a national congress on Type 1 diabetes for health professionals.

Conclusion: Over the last decade, T1 Diams has successfully been able to empower its patients, through its therapeutic education program, to become autonomous in the management of Type 1 diabetes. T1 Diams plays an important role in the management of Type 1 diabetes in Mauritius.

Keywords: Type 1 diabetes, T1 diams, non-profit organisation, therapeutic education, diabetic camp

Volume 6 Issue 1 - 2018

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Received: December 09, 2017 | **Published:** February 22, 2018

Introduction

Type I diabetes

Type 1 diabetes is a chronic condition where there is an auto destruction of the insulin producing cells (β cells) in the pancreas.¹ The treatment of Type 1 diabetes is lifelong and challenging one so it has to be managed successfully. A multi-disciplinary team is necessary with the aim of empowering the patients to acquire the necessary skills so as to become autonomous in the management of their condition.² By giving them the necessary knowledge and competence they can achieve excellent glycaemic control and personalized target HbA1c (HbA1c).³

The World Health Organisation (1998) has found that despite the treatment being efficient, its quality is far from acceptable.² For many years it has been proved that the nonadherence rates for chronic illness regimens and for lifestyle changes is about 50%.⁴ Kurtz⁵ also acknowledged that patients with diabetes are especially prone to substantial regimen adherence problems. As an illustration, Glasgow

et al.⁶ showed that adherence rates of 65% were reported for diet but only 19% for exercise.

Recently in 2005, the Cross-National Diabetes Attitudes Wishes, and Needs (DAWN) Study showed patient-reported adherence rates for medication in Type 1 diabetic patients was 83%, SMBG (self-monitoring of blood glucose) adherence was 70%, appointment keeping adherence was 71%, diet adherence rates were 39% and for exercise they were only 37%.⁷

Patients are ineffectively educated about their disease and few have been able to manage their chronic condition alone. Even though most doctors are highly efficient in diagnosing and treating diseases, they unfortunately fail to properly educate their patients on their disease.²

Importance of therapeutic patient education (TPE) for type I diabetes

Therapeutic patient education is intended to empower patients with the skills of self-managing or adapting treatment to their particular chronic disease, and in coping processes and skills. The

patient being autonomous in managing their condition will prevent avoidable complications (risk of diabetic ketoacidosis will be low), while having a good quality of life. Furthermore this reduces the cost of long-term care of type 1 diabetes to the society.² Muhlhauser & Berger⁸ demonstrated the effectiveness of TPE in Type 1 as well as Type 2 diabetes' management.

In France whenever there is a newly diagnosed diabetes, the guidelines issued by the French National Authority for Health (Haute Autorité de Santé [HAS]) says that therapeutic patient education (TE) should be implemented as soon as possible and by a multidisciplinary team, including mainly physicians, nurses and dieticians.⁹ The Law HPST (Hôpital Patient Santé Territoires) has laid down the foundations therapeutic patient education. The law clearly shows the conditions needed to implement a therapeutic patient education program it is part of the criteria for accreditation of healthcare facilities.¹⁰

In U.S, the National Standards for Diabetes Self-Management Education are designed to define quality DSME and support and to assist diabetes educators in providing evidence-based education and self-management support. They have set 10 standards which Diabetes Self-Management Education (DSME) programmes that should be met to ensure that people with diabetes are being provided with excellence in self-management support (Figure 1).¹¹

National Standards for Diabetes Self-Management Education and Support

10 Standards	
1. Internal Structure	6. Curriculum
2. External Input	7. Individualization
3. Access	8. Ongoing Support
4. Program Coordination	9. Patient Progress
5. Instructional Staff	10. Quality Improvement

Figure 1 National standards for diabetes self management educations and support.¹⁵

Since 1956, "L'Aide aux Jeunes Diabetiques" (AJD), France, is an association which endeavours to help insulin-dependent patients assume responsibility for the management of their disease and lead normal lives through their therapeutic program.¹²

The patient lives with the disease every day and does the hard work to manage it. So the educator's role, primarily, is to make that work easier.¹³

Methods

This retrospective observational study was carried out from March-April 2015. The author was given a contract of consultancy to evaluate all the therapeutic patient educations carried out by T1 Diams. The author was given the permission to be an observer during home visits, recreational diabetic days and went through all documentations (protocols, videos, photos etc.) pertaining to their annual diabetic camp.

This retrospective study was carried out from March-April 2015. The author was given a contract of consultancy where he evaluated all the therapeutic educations carried out by T1 Diams. The

managing committee of the organisation gave its approval so that the author participates in several of the therapeutic educations sessions. Furthermore the author was requested to sign a non disclosure agreement so that all information of patients is kept confidential.

Results

T1 Diams and type 1 diabetic therapeutic education in mauritius

In Mauritius there are a number of constraints pertaining to diabetes care, such as:

- Failure by both public and private clinics/hospitals to offer therapeutic patient education and training as an integral part of their diabetes care service;
- The need for diabetics to travel to health service centres to obtain essential information. There are time and financial implications to this, including work and school disruptions;
- Lack of type 1-specific training and education in general.
- severely limited access to pre-condensed and customised information and training in the public health service;
- Absence of a follow-up system to ensure post-training skills application and therapeutic compliance.

T1 Diams (Type 1 Diabetes Mellitus Support) is a Mauritian non-profit organisation specialised in the care and self-management of Type 1 Diabetes in Mauritius and was founded in 2005. In 2007, with the collaboration of Children's Hospital, in Reunion Island, they set up the first therapeutic education programme in Mauritius. It was founded by 8 parents of type 1 diabetics and today in 2015 they have reached 241 patients. During the last 10years, T1 Diams has been successfully been developing and implementing of diabetic therapeutic education.

They achieve their goals by 4 types of therapeutic educational interventions:

- Regular home based diabetes therapeutic education
- Regular diabetic recreation day
- Annual winter diabetic camp
- Trimestral news bulletin on Type 1 diabetes and an annual national congress on Type 1 diabetes for health professionals.

The association has one general practitioner, 2 diabetes educators, 1 dietician, 1 psychologist and 1 counsellor working on a full time basis. There are also health care professionals who collaborate with the association. Whenever there is newly diagnosed Type 1 diabetes, in the private or public sector, the doctor will refer the case to T1 Diams for therapeutic education. T1 Diams will do the diabetes self-management education and the doctor will deal with the therapeutic side.

T1 Diams: type 1 diabetes education program

T1 Diams' Type 1 diabetes education model is inspired from Aides aux Jeunes Diabetiques (AJD), France and National Health Authority (HAS) France. The program consists of four main steps: the educational diagnosis, development of a personalized program, implementation of the program, and evaluation.

Educational diagnosis

Whenever a new patient and its family are referred to the association, one of the diabetes educators along with a medical practitioner will do an educational diagnosis. This step is essential to identify the needs and expectations of the patient; it serves to identify obstacles and resources to ensure the success of the TPE; it also enables the compilation, with the patient, of a list of skills that they must acquire or use. T1 Diams use the AJD based 50 questions questionnaire to evaluate the initial knowledge of the patient and family. Furthermore the social counsellor will do a Motivational Interview to assess the patient's support network, their psychological, social and occupational vulnerabilities, and their receptiveness to the TPE proposal. The conversation between the multidisciplinary team and the patient is done in a friendly atmosphere using open questions.

Development of a personalized program

The skills to be developed are negotiated with the patient. They must be realistic and accessible. The skills that the patient must be acquired are summarized in Table 1. Moreover patients enrolling on this program should also attend the diabetic recreation day and the winter diabetic camp of the association.

Table 1 Themes to be covered in the TPE

Objectives for the patient

Type 1 Diabetes

Injection techniques and blood glucose monitoring

Theme 1: Brief general description of the digestive system ,What is Type 1 diabetes

Theme 2: Hypoglycemia

Theme 3: Hyperglycemia

Theme 4: Insulin and adaptation

Theme 5: Nutrition

Theme 6: Personal experience(nutrition, social aspects and physical activities)

Implementation of the various types of TPE

Home visits: In T1 Diams, the particularity of the therapeutic patient education is that it is done during home visits. The diabetic education program of T1 Diams is not only targeted for the patient but the family members as well. Each of the themes, in Table 1, is associated with a well-defined protocol and with its respective support materials. Every week each educator will do home based therapeutic education where the member and family is present. Each theme is covered every 2 to 3 weeks. As an illustration, when the diabetes educator arrives at the member's place, first 10mins for summary of the last visit, then next 30mins therapeutic education between the patient and the diabetes educator. And the last 10mins they both assess what they want to work on for the next visit. The duration is 1hour maximum. Every time a questionnaire is used to assess diabetes knowledge and quality of life (SF 36) before and at the end of the program. After 12weeks, these patients are reviewed at the office of T1 Diams and on monthly recreational diabetic day. The Hvidoere expert opinion presented by Cameron F, showed that, most diabetes care team agreed, to improve metabolic outcomes we must have more usual clinical care (time, visits, staff etc.).¹⁴ Annually there are about 1000 home visits for the 241 members.

Diabetic recreation day (T1 diams en Ballade and enjoy life)

T1 Diams regularly organise a monthly recreational diabetic day (Enjoy life or T1diams en ballade). About 40patients normally attend this day and they are divided in groups of 10, each taken by diabetes educators. The morning session is dedicated to diabetic therapeutic education. Various educational tools are used (written documents, slides, internet, etc.). In the afternoon session there are physical activities. Specialist doctors are also invited to do a presentation on a specific subject. These diabetic recreation days give an opportunity for parents to be assured that their diabetic children can be autonomous. The day is carried out in a professional way so as to empower the patients. These activities should be organised regularly during a year. These collective sessions are suitable for experience sharing.

Annual winter diabetic camp

In the Republic of Mauritius (an island in the south-west of the Indian Ocean), since 2007, T1Diams have been organising a yearly diabetic camp of seven days duration during the winter season for its members and their families. Two age groups are present (0 to 11years and 12 to 25years). For the first group the children are accompanied by their parents while the second groups come on their own. During the camp, therapeutic education is carried out. The acquisition of knowledge and self-care skills are ensured through pedagogical diabetes related games and presentations. Physical activities as well as workshop on carbohydrate counting are also organised. Those activities help the participants acquire and maintain the skills that are *sine qua non* to live optimally with their disease. During the camp, there are also interventions from professionals (nutritionist, psychologist, social worker, endocrinologist, ophthalmologist, podiatrist and dentist) so that they get a complete medico-social follow-up.

Trimestral news bulletin on Type 1 diabetes and an annual national congress on Type 1 diabetes for health professionals.

Every 3months the association publish a review to its members and the public on type 1 diabetes. Furthermore during the month of November they organise a symposium on Type 1 diabetes to the healthcare providers.

Evaluation of the TPE programme

Evaluation of the TPE programme is an ongoing process.

The evaluation is made at four different levels:

- i. Levels of knowledge: the AJD questionnaire is done after the program to evaluate the knowledge acquired (a considerable increase in knowledge was noted).
- ii. Skills: the patients attending the diabetic recreation days and the diabetic camp have the opportunity to show to others the skills that they have acquired efficiently.
- iii. Blood results: each 3months, the glycyated haemoglobin is measured to assess the control of the type 1 diabetes.
- iv. Psychological outcomes (results from SF 36forms showed a 20% increase in satisfaction rate).
- v. Coordination of participants
- vi. The programme coordinator has a fundamental role. The latter will ensure the smooth ongoing of the programs.

Conclusion

Over the last decade, T1 Diams has successfully been able to empower its patients, through its therapeutic education program, to become autonomous in the management of Type 1 diabetes. T1 Diams plays an important role in the management of Type 1 diabetes in Mauritius.

Acknowledgments

We are grateful to Mr. Didier Jean Pierre, Mr. Abdullah Dustagheer, Ms. Bianca Labonté, Ms. Mansha Chummun, Dr Baptiste Valle and Dr. Zahrah Atchia for their technical help and general support for this article.

Conflicts of interest

The authors declares that there is no conflict of interest.

Funding

None.

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