

## Short Communication

# Lay Led's as Educators: Adapting a Self-Management Educational Program for Adolescents with Diabetes Type 1

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### Abstract

The current health guidelines aim to increase the responsibility of people with chronic conditions to self-care, emphasizing the important role of health professionals in their empowerment and self-management skills education. The literature has highlighted educational programs for self-management of chronic condition as a holistic approach involving not only special health needs (treatment, therapy, physical well-being and functionality) but also the emotional, psychological and social needs. Some authors have proposed the use of self-management educational programs emphasizing the importance of the use peers, "Lay-Led's", (self-management experts on the same chronic illness) as mentors on programs, like Lorig and Holman with adults and elderly population, and Malheiro with adolescent's with spina bifida [1,2]. These programs have shown to be effective, with positive health outcomes, such as an improvement in adherence to therapy, functionality, and decrease the use of emergency services and hospitalizations and reducing health costs. Thus, based on the education program designed by Malheiro we propose to adapt and implement this education program for self-management to adolescents with Diabetes Type 1 (DM1), using lay-led as educators, and evaluate their effectiveness on self-management competences, quality of life, self-efficacy, physical activity motivation, self-concept, HbA1c, variability in heart rate, blood pressure, body mass index, anthropometric profile. This is a project distinguished by the innovative methodologies and strategies used like: mentoring between peers (social persuasion); lay led's (modeling) and the psychoeducational strategies used in the sessions (e.g. questioning, brainstorming, problem-solving, roleplaying, self-monitoring).

**Keywords:** Adolescents; Diabetes Type 1; Lay-Led's; Self-Management Program

### Background

The technological advances and the increasing development of pediatric health knowledge have contributed to the increase of life expectancy of children whose survival would otherwise be unlikely. So, it has contributed also to the growth of child's morbidity rates and therefore a significant number of these children have special needs.

In the last years the survival rate of these children until adulthood increased significantly. The high incidence of child morbidity changed the focus of the pediatric health care to a major concern with adolescents and their transition to

adulthood. The present healthcare system is not prepared to give an adequate response to this newreality.

The Diabetes Type 1 (DM1) in children and adolescents, namely in Portugal, showing a significant increase in the incidence and prevalence. Living the adolescence with DM1 is particularly difficult since it is associated with development needs such as the conquest of autonomy and independence. The long-term consequences of an inadequately controlled DM1 give rise to severe complications in children and adolescents. The adapting process to this condition and its management are one of the most important challenges of the adolescent's life. In agreement with Portuguese Order of Nurses, the pediatric care in the community is clearly inadequate, a situation that has been causing for concerned policy responses to the high prevalence of chronic disease and high

costs in health [3].

Thus, the health policies around the world are looking to increase the responsibility of people with a chronic condition for self-care, without forgetting the important role of health professionals on their empowerment and promotion of self-management competences [2]. In response to this problem, psychoeducational strategies have been emphasized, in order to facilitate the development of self-management competences related to chronic conditions. This reality has been progressively recognized by health policies, which bet on a significant involvement of patients in their care. The effectiveness of psychoeducational interventions has been proved by scientific evidence in adults and elderly people with chronic conditions [1,4,5]. The authors highlight the education programs for self-management of chronic conditions as a holistic approach that involves not only the special health care needs of the person with a chronic condition (treatment, therapeutics, physical well-being and functionality) but also emotional, psychological and social issues [4]. The health benefits associated with this practice are reflected in less hospitalizations and complications, sustained at good levels of adherence to therapeutic regimens, and promote positive behaviors in adherence to treatment in adolescents with asthma and diabetes [5,6].

Lorig and Holman developed a program of education for self-management: "Expert Patients Program" evidencing its effectiveness on the development of self-management competences in adults and elderly patients with chronic conditions. These authors were pioneers in using peer's experts on self-management of their own chronic condition as mentors on self-management programs. This method showed positive results and reduced the financial costs of the programs, as it used only volunteer workers. In late 2005, the concept of "Lay-Led" or monitors who are experts in self-management was officially introduced. The programs that used trained Lay-Led's in the intervention with groups, supervised by a health professional, revealed significant behavior improvements related to the therapy adherence, management of symptoms and tertiary prevention. The results are also encouraging regarding the improvement of the health status and the decrease in the use of emergency services and hospitalizations[1].

Based on Lorig's intervention model "Expert Patients Education", Malheiro designed the "Educational Program for self-management on adolescents with Spina Bifida" [1]. Although the main theory has been sustained in the concepts of efficacy, self-regulation, and modeling of the Bandura Socio-Cognitive Theory, it also had the influence of some theories which also guided the development of this program until its final version [7].

Additionally, it has been recognized that many behavioral risk factors are associated with the secondary chronic condition

[8] and may have a significant impact on the functionality, wellness, and quality of life of youth [9]. Kaplan refers to three levels of intervention within the programs of education for self-management, at the level of Primary, Secondary and Tertiary Prevention, which are the objectives of the program, deciding which levels of prevention that the educative intervention should focus [10].

The Health Beliefs Model is a frame of reference used to understand the health behavior and has been extensively used in health education programs [11]. Theory of planned behavior also appears as a theory to explain how the influences determine the decision of the individual in relation to the performance of a particular behavior. This theory assumes that people usually behave in a rational form and that they control this behavior. Thus, the behavior depends on individual motivation (behavioral intention) and self-belief in the ability to perform it (perceived behavioral control) [12].

This suggests that the intervention must include strategies to help young people develop contingency plans and to prepare themselves for the proper performance in different situations and more difficult to achieve [9]. According to Lorig, the Transtheoretical Model of Health Behavior Change by Prochaska, DiClemente and Norcross enables the evaluation of the success level of participants and identifies the phases in which they are more successful (e.g. from contemplation to preparation) [10,13].

In addition, Green has developed the PRECEDE-PROCEED Model (Predisposing, Reinforcing and Enabling Constructs in Educational/Ecological Diagnosis and Evaluation and Policy, Regulatory and Organizational Constructs in Educational and Environmental Development), to help the design of public health programs. This constitutes an important tool for planning health promotion programs and involves all stages from identification of needs to the evaluation of the results, so it was a very useful tool in planning an interventionsuch as this educational program [2].

Lorig stresses the importance of Self-Monitoring Behavior. The monitoring of the participants' behavior is an ongoing and essential process throughout the program, not only to allow them to identify their stage in the change process but also to promote reflection about what they can do and what they need to change. The author suggests the use of a personal diary, to promote the writing on the action and awareness of what has failed a process that induces the action [9].

Also, the Social Support is often incorporated into programs for being an important source of motivation for participants. There are several ways to encourage the social support. Suggesting the participants with opportunities to help others is an excellent way to engage participants in the program.

The potential for success increases with a structured program, to provide opportunities for participants to give and receive knowledge, by implementing a mentoring system between the participants (adolescents) [9]. This was a successful strategy in the program performed by Malheiro with adolescents with spina bifida [2].

The benefits associated with the psychoeducational strategies used in the Educational Program for Self-management on Adolescents with spina bifida (resolution of problems, roleplaying, plan of action and modeling) are clearly evidenced by the adolescents with spina bifida and associated with an improvement in their self-management behaviors. The results highlight the importance this program had on activities of daily living performance, problem-solving and decision-making competences about their own health condition [14].

## **Self-Management Educational Program for Adolescents with Spina Bifida**

The “Educational Program for Self-Management on Adolescents with Spina Bifida, developed by Malheiro consisted of seven sessions that obey the following protocol (during the morning or afternoon) [2]:

- Brief introduction to the topic (all sessions have a different theme).
- Questioning (identify the knowledge of participants about the subject in focus).
- Brainstorming Problems (list the problems identified by participants in relation to the issue raised at the meeting); Problem solving Technique, using some of the problems identified (the most frequent), and ask the group for possible ways of solving (list solutions), and discuss with the group the advantages and disadvantages of the proposed resolution.
- Roleplaying: simulation of two or three problem situations (previously identified in an exploratory study).
- Brief Lesson (summary presentation slides of some key points related to the topic discussed at the meeting and viewing of short videos of simulation performed by monitors/ Lay Leds).
- The elaboration of the action plan (at the end of each session. All participants undertake to change, at least, one behavior related to the theme of the session they think they want to and they are able to change during the week and note it on their “Individual Diary”).

Each session seeks to work a distinct area, encouraging each participant to work with and for their peers, promoting the reflection of the learned contents in previous sessions. Each session corresponds to a specific area to develop. However, the sessions’ aim is not only the promote skills in the specific

subject in question, but also the promotion of a reflection that allows a coherent articulation with the knowledge’s developed in previous sessions in order to give an adequate response to the problems identified.

At the beginning of the program, the mentoring system is implemented with the following guidelines: the tutors are selected from among the participants by age (older) and not by ability and autonomy (half of the group participants are tutors of the remaining half). The mentors (Monitors/Lay Leds) must help in any problems that tutors might have with their pupils and check if the checklist is being filled out properly (Individual Diary with a checklist of two procedures to be carried out e.g. self- catheterization and monitoring skin) and must answer to supervision, support and orientation needs of the tutor or pupil that he/she is responsible for.

At the end of the program, all the Individual Diaries are collected and subjected to an evaluation by the team coordinator and monitors/Lay Led’s, regarding the accomplishments in completing the checklists and the action plan. The two best couple (mentor and mentoring) are selected for the award of prizes. The two tutor winners are nominated to be Lay Leds on the next program.

In this program intervention on the adolescents with spina bifida, their personal experiences are shared with the group. This seeks to provide a set of experiments aimed to optimize the development of skills of self-management in participants. The benefits associated with the psychoeducational intervention strategies used in the program of education for self-management of the condition with young people with Spina Bifida (problems solving, roleplaying, plan of action and modeling) were clearly evidenced not only by the adolescents, but also by their parents/ caregivers after six months of living with them at home after the program. They show behaviors that are associated with a clear improvement in self-management of their condition [2]. The changes in adolescent behavior by assuming the role of mentor highlight the effectiveness of this strategy and the great potential it may have in the area of education by peers with chronic illness [14].

It is also important to highlight that the existence of reference models with the same chronic condition (Lay Led’s) was a key factor to facilitate the learning process, since this person, who had experienced the same difficulties, could provide the best strategies to overcome them [14]. With this project, we validate the evidence that supports the theory that the use of Lay Led’s, in programs with adolescents with a chronic condition and special needs is effective in developing skills of self- management. Some changes in the clinical practice may be justified, facing the need to promote the self-management of the therapeutic regimen in children and young people with chronic condition/disability and facilitating their transition to adulthood.

Regarding the programs of self-management directed to adolescents, the advantages have been proved through the psychoeducational strategies used by Malheiro [2]. Considering the possibility of being adapted to young people with other chronic diseases, and constituting an important milestone in the development of mastery in adolescents, it can be used as a facilitator of transition to adulthood, and thereby improve the quality of life-related to health and well-being.

## Self-Management for adolescents with Diabetes Mellitus Type 1

In 2014, Portugal had 1444 cases of Diabetes Type 1 (DM1) in young people, aged between 14-19 years, and 303 new cases in children aged between 0 to 19 years, showing a significant increase in the incidence and prevalence of type 1 diabetes in this population [15]. The long-term consequences of an inadequately controlled DM1 give rise to severe complications, such as neuropathy, nephropathy, and retinopathy, among others. These in turn cause possibly changes in health conditions like hypertension, chronic kidney disease or decreased visual acuity [16].

Children with DM1 have health needs that may cause serious complications and even put their lives at risk if they are not properly addressed and treated. A good disease management can prevent or delay secondary conditions and the complications. The adolescence with DM1 is particularly difficult since it is associated with development needs such as the conquest of autonomy and independence. This condition and its management are one of the most important challenges of the adolescent's life.

The recognition of practices that are successful in promoting self-management skills, not only in other countries of Europe but also by national researchers, could be an important international model to adapt. The National Health System in the United Kingdom, for example, in order to reduce health care costs associated with increased life expectancy and, the high incidence of chronic conditions [17], in 2002, introduced the Expert Patient Program, in some pilot services in the country. In the face of the success obtained, in 2005 the Expert Patient Program was integrated into the National Health Program [18].

According to Regulator Community Interest Companies & Department for Business, Innovation & Skills office, in 2013, around 5000 courses had already been taken, forming 848 participants (Lay Led's). The results are mainly in diabetes population [2]. Education for chronic disease self-management has been considered by health policies like a priority by the high costs inherent to the conditions arising from a poor adherence to treatment of DM1 in adolescents (recurrences of emergency, neuropathy, nephropathy and renal failure). This project aim responds to this population.

The intervention in the adolescent with DM1, concerning the development of skills that enable them to perform daily life activities in an independent way, should be started as early as possible, within a multidisciplinary approach involving all professionals of health, nutrition, and sports education. With the increase of life expectancy, some aspects related to the health of youth/adults also benefit with the autonomy. The prevention of secondary conditions such as kidney failure may be crucial, not only for the adolescents, with the prevention of micro and macrovascular damage (neuropathy, retinopathy and nephropathy), but also for society as a whole to avoid spending an exorbitant in treatments of hemodialysis for kidney failure (450€ per session, during 12 months=64,800 € per year).

In an RCT Diabetes Control and Complications Trial, that involved 1441 participants with DM1, 195 adolescents over the age of 13 years old. The results showed that only a good control glycemic index prevents or delays the secondary conditions associated with Type 1 diabetes (retinopathy, neuropathy, nephropathy, and cardiovascular diseases). We can conclude, that the key to delay or prevent the secondary conditions it is an early and effective intervention to the adolescent with DM1 and family based on an educational program for self-management, associated with physical activity practice [19].

This project intends to prove the effectiveness of a program already validated by Malheiro in 2016 [2] on adolescents with Spina Bifida, in adolescents with DM1. Promoting self-management skills development, improving their quality of life-related to health, adherence to therapy (insulin administration, monitoring of glycaemia, management of hypoglycemia), decrease the number of recurrences to emergency services and hospitalizations, decrease the levels of HbA1c, heart rate variability, respiratory rate, blood pressure, body mass index, anthropometric profile, increase the motivation for physical activity, dietary control, self-efficacy and self-concept.

### Purpose of Study

- To adapt an educational program for self-management validated on adolescents with Spina bifida to adolescents with DM1.
- To assess the effect of the program on Self-concept, Self-management, Quality of life related with health, Physical activity motivation, Self-efficacy on DM1, HbA1c, Cardiac rate variability, Respiratory rate, Blood Pressure, anthropometric profile.

## Methods

### Participants

Will be involved in this project, adolescents with DM1, ages between 16-19 years old who agree to participate in Summer Camp

and carry out the Educational Program for Self-management on Adolescents with DM1

### 1.1. Instruments

Sociodemographic and clinic characterization questionnaire of participants (adolescents); Diabetes Self-Management Questionnaire - Revised (DSMQ-R) (Andreas Schmitt, 2015) (will be translated, adapted and validated to Portuguese Adolescents with DM1 in this study); Self-Efficacy DM1 (Grossman, Brink & Hauser, 1987) translated, adapted and validated to Portuguese population by Pereira e Almeida (2004); Self-perception Profile for Adolescents (Susan Harter) translated, adapted and validated to Portuguese Adolescents by Peixoto, Alves-Martins, Mata, and Monteiro (1996); Quality of life Scale- Kidscreen; Motivation for Physical Activity Questionnaire (David Markland) translated and adapted by Alves and Lourenço (2001); Collection of blood for HbA1c and lipid profile; Cardiac rate variability; Blood pressure; Respiratory rate; anthropometric Profile.

### Procedures

The study design has three steps:

- 1st Step - the Program Adaptation to Adolescents with Diabetes type 1 (where we are presently doing the exploratory studies)
  - Study I - Factors influencing the development of self-management in adolescents with Diabetes Type 1: a scoping review protocol;
  - Study II - LayLeDU DM1 - Development of Self-Management Competences in Adolescents with Diabetes Type 1. Listen to their voices and their parents (Focus Groups interviews young adult with DM1 and caregivers separately);
  - Study III - Translation, Adaptation, and Validation of "Self-Management Diabetes Questionnaire" on Portuguese Adolescents with Diabetes Type 1.
- 2nd Step - Program Implementation and assessment, before and after (T1 and T2) (quantitative and qualitative approach)
- 3rd Step – Follow- up assessment / 6 months after the program (T3) (quantitative and qualitative approach)

### Main Argument

It can be assumed that it will be an important contribution in the quest for solutions, health improvement, preventing secondary conditions of adolescents with DM1, and implicitly improve their quality of life and of their families. It is predicted to decrease the health expenses considerably as we can see in the United Kingdom Health System.

A multidisciplinary team, (built from Nursing School, Sport School, Nutrition and Dietetic School and Diabetic Association experts in collaboration with the partners involved: hospitals

ambulatory pediatrics' services) will adapt the program, plan and train the monitors and the Lay Led's (young adults experts in the self-management of DM1) and collaborate in the recruitment of the adolescents with DM1 for the program implementation. This team will also evaluate the effect of the program (quality of life related to health; adherence to therapy; HbA1c; variability in heart rate, blood pressure; body mass index, anthropometric profile, motivation for physical activity, dietary control, self-efficacy and the self-concept) on three times (before they start the program T1, after finish the program T2 and on follow-up at 6 months).

The project is distinguished by its innovative nature of the methodologies and strategies used as the:

- Mentoring between peers (persuasion);
- Lay Led's (education for young adults, experts in the self-management of DM1);
- The psychoeducational strategies used in the sessions (questioning, brainstorming, the technique of problem-solving, roleplaying, self-monitoring, modeling and the actionplan).

We propose to implement this program, as well as to assess its costs and benefits for the adolescents' health with DM1, over the next two years. We are currently in the 1<sup>st</sup> step: identification of influential factors on the development of self-management skills (scoping review, focus groups with young adults and their parents), adaptation of the educational program to self-management, recruitment and training of monitors / Lay Led's and recruitment of participants.

### Conclusion

With this project, we seek to validate the evidence that supports the theory of the use of Lay Led's in programs with adolescents with a chronic condition and special needs are effective in developing skills of self-management, specifically on DM1 condition. Also, may justify some changes in practices to promote self-management skills of the therapeutic regimen in children and young people with DM1 and facilitating their transition to adulthood.

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