

Lay-leds as Educators: A self-Management Educational Programme for Adolescents with Chronic Conditions

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Suggested Citation:

Malheiro, M. I. D. C., Graca, M. G. V. & Figueiredo, I. C. (2017). Lay Led's as educators: A self-management educational program for adolescents with chronic conditions. *New Trends and Issues Proceedings on Advances in Pure and Applied Sciences*. [Online]. 08, pp 68-75. Available from: www.propaas.eu

Selection and peer review under responsibility of Prof. Dr. Afsun Ezel Esatoglu, Faculty of Health Sciences, Ankara University, Turkey.

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Abstract

Current health guidelines aim to increase the responsibility of people with chronic conditions to self-care. Literature studies highlight educational programmes for self-management of chronic conditions as a holistic approach, involving special health needs and emotional, psychological and social needs. Lorig and Holman (with adults and the elderly population) and Malheiro (with adolescent's with spina bifida) have proposed self-management educational programmes, using 'Lay-leds', as mentors on programmes. These programmes have proven effective, with positive health outcomes, such as improvement on adherence to therapy, functionality and decrease of use of emergency services and hospitalisations and reducing health costs. Thus, we propose to adapt and implement this education programme for self-management of adolescents with diabetes type 1, using Lay-leds 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 and anthropometric profile.

Keywords: Self-management programme, adolescents, chronic conditions, Lay-leds.

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1.Introduction

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

The survival rates of these children until adulthood increased significantly. The high incidence of child morbidity changed the focus of paediatric 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 new reality.

In agreement with the Portuguese Order of Nurses, paediatric care in the community is clearly inadequate, a situation that has been a cause for concerned policy responses to the high prevalence of chronic disease and the high costs in health [1].

Thus, health policies around the world are looking to increase the responsibility of people with chronic conditions 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 emphasised, in order to facilitate the development of self-management competences related to chronic conditions. This reality has been progressively recognised 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 [3, 5]. The authors highlight the education programmes for self-management of chronic conditions as a holistic approach that involves not only the special healthcare 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 the decrease in hospitalisations and complications, sustained at good levels of adherence to therapeutic regimens, and promoting positive behaviours in adherence to treatment in adolescents with asthma and diabetes [5, 6].

Lorig and Holman developed a programme of education for self-management: 'Expert Patients Program', evidencing its effectiveness on development of self-management competences in adults and elderly patients with chronic conditions. These authors were pioneers in using peers experts on self-management of their own chronic condition as mentors on self-management programmes. This method showed positive results and reduced the financial costs of the programmes, 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 programmes that used trained Lay-leds in the intervention with groups, supervised by a health professional, revealed significant behaviour 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 hospitalisations [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 modelling of the Bandura Socio-Cognitive Theory, it also had the influence of some theories that also guided the development of this programme until its final version [7].

Additionally, it has been recognised that many behavioural 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 programmes of education for self-management, at the levels of primary, secondary and tertiary prevention, which are

the objectives of the programme, deciding which levels of prevention the educative intervention should focus on [10].

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

This suggests that the intervention must include strategies to help young people develop contingency plans and to prepare themselves for proper performance in different situations and those that are more difficult to achieve [9]. According to Lorig, the Transtheoretical Model of Health Behaviour 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 Organisational Constructs in Educational and Environmental Development), to help the design of public health programmes. This constitutes an important tool for planning health promotion programmes and involves all stages from identification of needs to evaluation of the results, so it was a very useful tool in planning an intervention such as this educational programme [2].

Lorig stresses the importance of self-monitoring behaviour. The monitoring of the participants' behaviour is an ongoing and essential process throughout the programme, 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 writing on the action and awareness of what has failed, a process that induces the action [9].

Also, social support is often incorporated in programmes for being an important source of motivation for participants. There are several ways to encourage social support. Suggesting the participants with opportunities to help others is an excellent way to engage them in the programme. The potential for success increases with a structured programme, 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 programme performed by Malheiro, with adolescents with spina bifida [2].

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

1.1. Self-Management Educational Programme for Adolescents with Spina Bifida

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

- Brief introduction of 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 on 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 behaviour 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 to promote skills in the specific subject in question, but also the promotion of a reflection that allows a coherent articulation with the knowledge developed in previous sessions, in order to give an adequate response to the problems identified.

At the beginning of the programme, 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-catheterisation 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 programme all the individual diaries are collected and subjected to an evaluation by the team coordinator and monitors/Lay-leds, regarding the accomplishments in completing the checklists and the action plan. The best two couples (mentor and mentoring) are selected for the award of prizes. The two tutor winners are nominated to be Lay-leds on the next programme.

In this programme intervention on adolescents with spina bifida, their personal experiences are shared with the group. This seeks to provide a set of experiments aimed to optimise the development of skills of self-management in participants. The benefits associated with the psychoeducational intervention strategies used in the programme of education for self-management of the condition with young people with spina bifida (resolution of problems, roleplaying, plan of action and modelling) 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 programme. They show behaviours that are associated with a clear improvement in self-management of their condition [2]. The changes in adolescent behaviour 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-leds) 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-leds, in programmes with adolescents with 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 programmes of self-management directed at 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.

1.2. 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 and 19 years, and 303 new cases in children aged between 0 and 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 possibly cause 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. 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 is one of the most important challenges in 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 healthcare 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 programme [18].

According to Regulator Community Interest Companies & Department for Business, Innovation & Skills office, in 2013, around 5,000 courses had already been taken, forming 848 participants (Lay-leds). The results are mainly in the diabetes population [2].

Education for chronic disease self-management has been considered by health policies to be a priority due to 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 sport 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 highly beneficial not only for the adolescents, with the maintenance of health and prevention of damage to the micro and macro vascular levels (neuropathy, retinopathy and nephropathy), but for the society as a whole, to avoid spending an exorbitant in treatments of haemodialysis for kidney failure (a situation more frequently) (450€ per session, during 12 months = 64,800 euros per year).

An RCT Diabetes Control and Complications Trial involved 1,441 participants with DM1, with 195 adolescents over the age of 13. The results showed that only a good control of the glycaemic index prevents or delays the secondary conditions associated with Type 1 diabetes (retinopathy, neuropathy, nephropathy and diseases of the cardiovascular forum). We can conclude that the key to retard or prevent the secondary conditions is early and effective intervention for adolescents with

DM1 and a family-based educational programme for self-management, associated with physical activity practice [19].

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

1.3.Purpose of Study

- To adapt an educational programme for self-management, validated on adolescents with spina bifida to adolescents with DM1.
- To assess the effect of this programme on: self-concept, self-management, quality of life related to health, physical activity motivation, self-efficacy on DM1, HbA1c, cardiac rate variability, respiratory rate, blood pressure and anthropometric profile.

2.Methods

2.1.Participants

Adolescents with DM1, aged between 16 and 19 years, who agree to participate in the summer camp and carry out the educational program for self-management on adolescents with DM1, will be involved in this project.

2.2.Instruments

Socio-demographic and clinic characterisation questionnaires for participants are (adolescents); diabetes self-management questionnaire – revised (Andreas Schmitt, 2015) (will be translated, adapted and validated to Portuguese Adolescents with DM1 in this study); self-efficacy DM1 (Grossman, Brink, and 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, e Monteiro (1996); Quality of life Scale- Kidscreen; Motivation for Physical Activity Questionnaire (David Markland) translated and adapted by Alves e Lourenco (2001); Collection of blood for HbA1c and lipid profile; Cardiac rate variability; Blood pressure; Respiratory rate; anthropometric Profile.

2.3.Procedures

The study design has three steps:

- First Step – the Program Adaptation to Adolescents with DM1 (where we are presently doing the exploratory studies)
- Study I: Factors influencing the development of self-management on adolescents with Diabetes Type 1: a scoping review protocol;
- Study II: Lay-LeDU DM1 – Development of Self-Management Competences in Adolescents with Diabetes Type 1. Listen to their voices and their parents (focus groups interview young adults with DM1 and caregivers separately);
- Study III: Translation, Adaptation and Validation of 'Self-Management Diabetes Questionnaire' on Portuguese Adolescents with Diabetes Type 1.

- Second Step – Program Implementation and assessment, before and after (T1 and T2)(quantitative and qualitative approach)
- Third Step – Follow-up assessment/6 months after programme (T3) (quantitative and qualitative approach)

3.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 paediatrics' services) will adapt the programme, plan and train the monitors and the Lay-leds (young adults experts in the self-management of DM1) and collaborate in the recruitment of adolescents with DM1 for the programme implementation. This team will also evaluate the effect of the programme on 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, before they start the programme (T1), after finish (T2) and at follow-up 3 and 6 months later.

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

- Mentoring between peers (persuasion);
- Lay-leds (education for young adults, experts in the self-management of DM1);
- The psycho-educational strategies used in the sessions (questioning, brainstorming, technique of problem solving, roleplaying, self-monitoring, modelling and the action plan).

We propose to implement this programme, as well as to assess its costs and benefits for the adolescents' health with DM1, during the current year. We are currently in the first step: identification of influence factors on development of self-management skills (scoping review, focus groups with young adults and their parents), adaptation of the educational programme to self-management, recruitment and training of monitors/Lay-leds and recruitment of participants.

4.Conclusions

With this project, we seek to validate the evidence that supports the theory for use of Lay-leds in programmes with adolescents with chronic conditions and special needs is effective for developing skills of self-management. Also, it may justify some changes in practices needed to promote the self-management of therapeutic regimens in children and young people with chronic condition/disability and facilitate their transition to adulthood.

Acknowledgements

This article presents independent research funded by Research Unit& Nursing Development from Nursing College of Lisbon. We gratefully acknowledge the support of the APDP team (Diabetics Association).

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