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ORIGINAL ARTICLE

EDUCATIONAL PROGRAM FOR SELF-MANAGEMENT ON ADOLESCENTS WITH SPINA BIFIDA: WHAT DO YOUTHS AND THEIR CAREGIVERS HAVE TO SAY?

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ABSTRACT

Objective: To evaluate an educational program and its effects on self-management skills, from the perspective of youths and their parents/caregivers.

Method: The present study conducted interviews in focus groups with 51 youths with spina bifida (10-18 years old) who participated in the program and 30 parents/caregivers.

Results: Improvements were observed in the youths' self-management skills, who displayed greater responsibility, proactivity, confidence, problem-solving skills and autonomy. In terms of the psychoeducational strategies used in the program, emphasis goes to the problem-solving technique, role-playing, videos, peer mentorship, and modeling (lay led model).

Conclusion: The results of the program showed that the youths built skills that fostered their autonomy. The changes observed in the youths on taking on the role of mentors point to the effectiveness of this strategy and its potential for children with chronic conditions.

DESCRIPTORS: Program; Education; Adolescents; Chronic Illness; Self-Management.

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ARTIGO ORIGINAL / ARTÍCULO ORIGINAL

PROGRAMA DE EDUCAÇÃO PARA A AUTOGESTÃO EM ADOLESCENTES COM SPINA BÍFIDA: O QUE DIZEM OS JOVENS E SEUS CUIDADORES

RESUMO

Objetivo: avaliar um programa e os seus efeitos nas competências de autogestão, na perspetiva dos jovens e de seus pais/cuidadores.
Método: entrevistas em grupo focal, com os 51 jovens com Spina Bifida (10-18 anos) que realizaram o programa e 30 pais/cuidadores.
Resultados: revelam melhoria no comportamento de autogestão dos jovens, mais responsáveis, proactivos, confiantes, competentes na resolução de problemas, e autónomos. Quanto ao programa, destacam as estratégias psicoeducativas utilizadas, como a técnica de resolução de problemas, o roleplaying, os vídeos, o regime de tutoria entre pares e a modelagem (Lay led's).
Conclusão: o programa obteve resultados positivos na capacitação dos jovens para a autonomia. As mudanças verificadas no jovem ao assumir o papel de tutor permitem destacar a eficácia desta estratégia e o seu potencial na criança com condição crónica.

DESCRITORES: Programa; Capacitação; Adolescentes; Condição Crónica; Autogestão.

PROGRAMA EDUCATIVO DE AUTOGESTIÓN PARA ADOLESCENTES CON ESPINA BÍFIDA: QUÉ DICEN LOS JÓVENES Y CUIDADORES

RESUMEN

Objetivo: Evaluar un programa y sus efectos en las competencias de autogestión, conforme la visión de los jóvenes y de sus padres/cuidadores.
Método: Entrevistas en grupo focal, con los 51 jóvenes con espina bífida (10-18 años) que realizaron el programa y 30 padres/cuidadores.
Resultados: Expresan mejora conductual de la autogestión de los jóvenes, más responsables, proactivos, confiados, competentes para resolver problema, autónomos. Respecto del programa, destacan las estrategias psicoeducativas utilizadas, como la técnica de resolución de problemas, el roleplaying, los vídeos, el régimen de tutoría entre pares y el modelado (Lay led's).
Conclusión: El programa tuvo resultados positivos en la capacitación de los jóvenes para su autonomía. Los cambios verificados en el joven al asumir el rol de tutor permiten destacar la eficacia de esta estrategia y su potencial en el niño con enfermedad crónica.

DESCRIPTORES: Capacitación; Adolescentes; Enfermedad Crónica; Autogestión.

Maria Isabel Costa Malheiro | Maria Filomena Gaspar | Luísa Barros

INTRODUCTION

In addition to the growing development of knowledge in the area of pediatric health, technological advances have increased life expectancy of children whose survival in the recent past was unlikely, while also contributing to an increase in the rate of child morbidity. Consequently, a significant number of these children present special needs. Spina bifida (SB), under the form of myelomeningocele, is one of these situations: a congenital malformation in which the neural tube fails to close completely during the embryonic stage of pregnancy. It is a complex condition that causes sensory-motor (paralysis and loss of sensation of lower limbs), urological (95% present neurogenic bladder, urinary incontinence) and intestinal (anal incontinence) disorders(1). These children are faced daily with highly complex tasks such as intermittent self-catheterization every 3 hours, intestinal training and skin monitoring (high incidence of pressure ulcers and skin injuries)(2).

Their survival rate up to adulthood increased significantly in the last decades (95%) (3). A high number of these youths reach adulthood still very dependent on their parents/caregivers to carry out activities of daily living (ADL). The literature describes children with SB as having lower levels of autonomy in decision making and carrying out self-care, especially in terms of bladder and bowel emptying, hygiene and transfers(4). A high percentage of adults with SB require assistance from family members for self-care (43% moderate and 24% minimal assistance) and to manage their condition(5).

Living with a disability requires youths with SB to be capable of managing a wide array of special healthcare needs with autonomy and independence, a challenge posed not only to individuals with SB and their families, but also to their healthcare providers.

Developing the skills to perform these tasks is essential to maintain the health of young people and also to transition to adulthood as smoothly as possible(2). Thus, this transition poses a challenge to healthcare professionals who work with these children, and the goal of nursing interventions is to facilitate the gradual transfer of responsibility for these special health needs from parents/caregivers to youths(6).

The development of self-management skills by young people with chronic conditions allows them to learn how to live, work, and actively participate in society, with knowledge about how to manage their condition and prevent short- and long-term complications. Even though maintaining physical health and improving motor functionality are important aspects, youths with SB need to develop self-management skills and independence so they can later "survive" in the adult world(7). This requires changing the focus of health care during childhood and adolescence, encouraging and promoting responsibility for their health management, thus preparing to take on roles inherent to adulthood(8).

Most adults with SB have the potential to be completely autonomous and lead a practically "normal" lifestyle. Children, adolescents or adults must be well equipped with skills, in order to reach a level of independence that allows them to "survive" in a competitive world, adequately managing their lives, which are usually complex(9). The process must begin in childhood and focus on promoting mastery over basic tasks, such as acquiring autonomy and actively participating in their community, thus achieving better quality of life and well-being(10).

Creating educational intervention programs that focus on functionality, from the perspective of development, can be the key to minimize disability and maximize abilities that allow these individuals to find adaptive strategies that foster more harmonious development that is as functional and autonomous as possible(9).

One answer to this problem is emphasizing psychoeducational strategies that seek to facilitate the process of adapting to a chronic condition. Among the various self-management education programs found in the literature, emphasis goes to the intervention developed by Kate Lorig, called the Expert Patients Programme. Lorig pioneered the use of lay led programs (role models with the same chronic conditions as participants and who are experts at managing their conditions), and scientific evidence from this program showed that it was effective among adults and older adults with chronic conditions(11). Later, the program was adapted to pediatric population by Malheiro and implemented among adolescents with spina bifida in a pilot study whose results point to a significant improvement in functionality levels(12) and self-management skills (problem solving relative to special care, responsibility for managing therapeutic regimen)(13). The authors described the advantages of using psychoeducational strategies in the program, with emphasis given by the adolescents to Bandura's self-efficacy reinforcement as the most effective, such as social persuasion (sharing experiences and problems with peers in similar situations) and modeling (the use of role models, videos, simulations and role-playing)(13).

Thus, to validate the effectiveness of the program, it was implemented with more than 51 adolescents with spina bifida and its effects on behavior were evaluated by the participants after carrying out the program as well as by their parents/caregivers six months after the intervention and living together in the household.

METHOD

This was a descriptive and exploratory study that represents the qualitative component of a larger quasi-experimental and longitudinal study. The authors recommend the mixed methods approach to enrichen the results with significant contextual information and a detailed description of the experience(14). Thus, at the end of the intervention, the program and its effects were evaluated by the youths (on finishing the program) and by parents/caregivers at follow up (six months living with youths at home).

The program consists of seven sessions (first session: "Living with spina bifida and the importance of autonomy", second session: Pressure ulcers - prevention and early detection", third session: Bladder emptying - self-catheterization", fourth session: "Bowel emptying - eating and physical exercise", fifth session: "Mobility and transfers", sixth session: "Hygiene/dressing & undressing" and seventh session: "Going home" (strategies to cope with overprotective behaviors) and qualitative assessment of the program through focus group interviews.

The program was implemented in two different groups. Group 1 consisted of girls (9:30 AM to 11 AM) and Group 2, of boys (11 AM and 12:30 PM), for seven days.

All the sessions followed a detailed protocol (support manual) with the following steps: Brief introduction to the topic; Questioning (identifying the knowledge of participants about the topic); Brainstorming problems (listing the problems identified by the participants regarding the topic of the session); Problem-solving technique, using some of the problems previously defined (the most common) and asking the group about possible resolutions (listing solutions) and discussing the advantages and disadvantages of the proposed solution; Role-playing: simulating two problems (identified through an exploratory study called Matrix Assessment); Brief lesson (summarized slide show and video presentation about key points relative to the topic of the session); Creating an action plan (at the end of each session, participants commit to changing at least one behavior relative to the theme of the session and recording it in their personal books).

During the program, a mentorship regimen was implemented according to the following guidelines: mentors were selected among the participants by age (half the group, the older mentored the other half). They supervised the records of their mentees every day and evaluated the action plans created at the end of each session (with an incentive, or a "prize" when this task was completed).

The sessions were carried out by the same nurse, and the lay leaders (female in the girls' group and male in the boys' group) conducted their groups with no incidents. The youths adhered to the program with enthusiasm and displayed active participation, asking questions, intervening, role playing and creating action plans.

Participants of this study included 51 patients with SB who fully completed the program, and 30 parents/caregivers. This study abided by all required ethical procedures (Helsinki declaration), and the researchers obtained the parents' and the youths' informed consent to participate in the study.

The present study was approved by the Scientific Committee of the University of Lisbon and the Research Ethics Committee of the Spina Bifida and Hydrocephalus Portuguese Association.

RESULTS

In terms of the characteristics of the participants, as illustrated in Table 1, the mean age of participants was 13.3 years, with 24 girls (47%) and 27 boys (52.9%).

Table 1 - Characteristics of participants (n=51)

Age	Mean 13.3 years
10-12 years	23 (45.0%)
13-15 years	10 (19.6%)
16-18 years	18 (35.2%)
Sex: Male/Female	24 (47%) /27 (52.9%)
Level of injury	
Sacral	18 (35.2%)
Lumbar	26 (50.9%)
Dorsal	7 (13.7%)
Walking Aids: Yes/No	39 (76.4%) /12 (23.5%)
Wheelchair	30 (68.8%)
Forearm crutches/braces	9 (17.6%)
Hydrocephalus: Yes/No	43 (84.3%) /8 (15.6%)
Main caregiver	
Mother	41 (80.3%)
Father	3 (5.8%)
Auxiliary institution	7 (13.7%)
Previous experiences with summer camps	
Yes/No	37 (72.5%) /14 (27.45%)
Region of residence	
South	30 (59.3%)
Center	13 (29.6%)
North	8 (59.3%)

Focus groups were used to gather data, a technique that has been commonly used by researchers in the social sciences. Gibbs defines this method as a carefully prepared discussion, whose objective is to gather data about how the group perceives any given area of interest(15). Furthermore, this discussion promotes interaction among the participants, and coupled with the interviewer's provocative stance, results in an environment conducive to spontaneity to unleash attitudes and emotions that would not likely be expressed in other situations(13).

The researchers conducted eight focus group interviews with 51 youths at the end of the program, and four focus groups with 30 parents/caregivers six months after the program.

Data analysis was conducted using Bardin's thematic content analysis, with some specificities relative to the focus group data collection technique(13).

To ensure scientific rigor, internal consistency was achieved through the agreement of the researchers' and the raters' interpretation. The analysis chart presented in Table 2 was constructed inductively and in accordance with the raters, and underpinned the global analysis model. As in the pilot study, every time the results presented a discrepancy and/or divergence, an intra-group analysis was conducted (youths and parents/caregivers)(13).

Table 2 - Analysis chart

DIMENSION	CATEGORY	SUBCATEGORIES	INDICATORS
ASSESSMENT	POSITIVE	Youth's behavior	Responsibility
			Proactivity
			Physical activity
		Self-perception	Self-efficacy
			Self-esteem
			Self-confidence
		Skills	Problem solving
			ADL autonomy
			Social interaction
	NEGATIVE	Youth's behavior	Regression
			Dependence

Seeking to learn about the opinion of youths and their parents/caregivers about the effect of the program on the youths' behavior was based on an approach focused on the assessment of the results of this experience and the reasons behind their opinions. In this dimension, two categories emerged from data analysis: positive evaluation (Table 3) and negative evaluation.

Table 3 - Positive evaluation of the summer camp program

CATEGORY	SUBCATEGORIES	INDICATORS	YOUTHS	PARENTS/ CAREGIVERS
POSITIVE	Youth's behavior	Responsibility	48	45
		Proactivity	8	28
		Discipline	3	6
	Self-perception	Self-esteem	14	37
		Self-confidence	16	16
		Self-efficacy	3	19
	Skills	ADL autonomy	39	65
		Problem solving	69	28
		Social interaction	55	22

The main reasons given for positive evaluations by both groups were the behavior changes of youths, self-perception and the skills developed throughout the process. In terms of behavior changes, both groups emphasized that youths presented more responsible behaviors when carrying out tasks relative to their special health needs.

"There was someone I was responsible for and that made me realize that I have to be responsible." (Y) "She came back more responsible...more grown up...she is more responsible, follows her schedule" (P)

The parents also mentioned greater proactivity and self-sufficiency of the youths relative to their self-care.

"...They ask for less help and only call me when they really can't do it!" (P).

Regarding self-perception, both groups referred to increased self-efficacy. *"I learned to be independent and to perform...my self-catheterization and I don't need my mother anymore" (Y), "More confident about doing things, excellent!" (P).* Increased self-esteem was also mentioned by youths: *"We feel useful and help the younger ones who are going through what we've already gone through"* (Y). This was also noticed by parents: *"She came home very positive and happy!"* (P).

The youths reported having acquired problem-solving skills, which were reflected in positive repercussions throughout their daily lives.

"...It was very important for us to be prepared for the problems that can occur...how other people solve their problems can help us in the future" (Y). These positive repercussions were also reflected in the parent's answers: "...She is more independent...she figures things out without having to tell me about it" (P).

The youths also reported greater independence in activities of daily living:

"(...) I've become more independent in everything, I packed my suitcase, I took care of all my things...It was important" (Y), "I don't need anyone's help anymore to catheterize at school and home!" "It's amazing, he's doing everything by himself at school and at home" (P).

They also reported improved social skills because of the social interaction opportunities provided by this experience.

"I made new friends for life (...)" "I met my boyfriend!" (Y) "She found a group of friends and that's very important, now I have to take her out to see her friends and I think she has a boyfriend (laughs)" (P).

The negative aspects of this experience reported by some parents include regression of some behaviors that had already been acquired and demonstrated during camp; they stated it was not complete regression, though. However, some parents recognized that they should continue with what they learned at home, not doing so because of convenience, and because it is easier and quicker to do things for their child.

Regarding the evaluation of the Educational Program for Self-Management, the youths mentioned positive and negative aspects relative to the themes of the sessions and the psychoeducational strategies adopted (Table 4).

Table 4 - Analysis chart with program evaluation

DIMENSION	CATEGORY	SUBCATEGORIES	INDICATORS
PROGRAM EVALUATION	POSITIVE	Theme of Sessions	Clinical Conditions/SB/SCI
			Tertiary Prevention
			Transfers
			Self-Catheterization
			Hygiene/Dressing and Undressing
			The Importance of Autonomy
		Psychopedagogical Strategies	Roleplaying/simulations
			Lay leaders/monitors with SB
			Modeling
			Problem solving
			Mentorship regimen
	NEGATIVE	Psychopedagogical Strategies	Mentorship regimen
		Theme of Sessions	Does not meet their needs
			Not very interesting

Regarding the positive assessments of the program made by youths, emphasis goes to some of the topic addressed, justified by the learning it brought them and also the psychoeducational strategies employed, as observed in Table 5.

Table 5 - Category: positive evaluation of the program

CATEGORY	SUBCATEGORIES	INDICATORS	YOUTHS
POSITIVE	Theme of Sessions	Transfers	50
		Clinical Conditions/SB	40
		The Importance of Autonomy	26
		Self-Catherization	21
		Tertiary Prevention	27
		Hygiene/Dressing and Undressing	26
	Psychopedagogical Strategies	Problem solving	78
		Roleplaying/simulations	57
		Mentorship regimen	54
		Modeling	40
		Lay leaders/monitors with SB	40

Relative to the subcategory "Theme of Sessions", the youths emphasized some areas they considered most important, such as wheelchair transfers and the SB condition: *"Learning more about our disease", "I learned many...things about spina bifida"; the self-catheterization procedure" "they know how to teach us because they also had to learn and that's a good thing"* (Y), and also the importance of autonomy in ADL: *"These sessions helped me realize the importance of being independent and doing things for ourselves, not always having our mother following us around"* (Y).

Regarding the psychoeducational strategies used in the program, the youths emphasized the problem-solving strategy: *"Realizing that we all have the same problems", "challenges to overcome... this helps (Y)"*, followed by role-playing/simulation and videos: *"more movies... with the monitors showing you how it should be done" (Y), "…pretending to be a father and mother and realizing what they go through to try to make us do things well, that was difficult" (Y), "…pretending to be a nurse and realizing how hard it is to explain things to us" (Y).*

The peer mentorship strategy provided them with benefits in terms of learning and gaining autonomy: *"I learned a lot" "to teach my mentee, I had to learn and know how to do it very well" (Y),"a great responsibility that prepares us to be monitors" (Y).*

The use of the lay led model was also recognized by the youths, not only because of the opportunity to learn from more experienced adults with SB, but especially because of the possibility of one day becoming monitors in the summer camp program: *"It's very important to have monitors with SB at these programs", "They know how to do things because they already had to learn", "My dream is to be a monitor" (Y).*

DISCUSSION

The aim of the present study was to assess the effects of an educational program on fostering self-management of adolescents with SB in the context of a training summer camp, from the perspective of youths and their parents/caregivers. The program was positively evaluated by the participants and their parents/caregivers. The greatest benefits were observed in terms of skills to carry out ADL and self-manage their condition, which were maintained after the program. The parents emphasized not only increased autonomy relative to ADL, but primarily in the proactive and responsible attitude the youths displayed when carrying out their special health needs.

Surprisingly, the participants had very little knowledge about their conditions and were very interested in learning more about SB, its implications and how it manifests. Even though 82% of youths had hydrocephalus (associated with Arnold Chiari syndrome) and ventriculus-peritoneal shunt, nobody could explain what it meant. The special interest demonstrated in the hygiene session - which included the early detection of pressure ulcers - may be related to the concern of these youths due to the high incidence of pressure ulcers(16).

The psychoeducational strategy most emphasized by the youths were dynamic and interactive, in which they had more fun and that allowed them to train self-management skills for their condition(13). Learning through problem solving allowed them to train this skill in various stages: identifying the problem, learning and reflecting about hypothetical solutions (as a group), assessing the advantages and disadvantages relative to the consequences of each option and decision making aimed at a solution. This methodology allows young people to gain confidence in their process of autonomy(17). This result had already been found in the pilot study and was confirmed in the present study. The participants reported feeling more confident, proactive and competent to solve their problems, which was confirmed by their parents/caregivers six months after living with their child at home.

Role-playing/acting out problem situations was also an important moment of learning for the group. The youths considered it a challenge to take on the role of parents or health professionals and experience by themselves the difficulties inherent to interventions aimed to change inadequate and harmful behaviors for health. Raising awareness about the benefits of good treatment adherence and confronting the nonadherence of the fictitious youth led the group to reflect and evaluate their own behaviors.

Also in the pilot study carried out by Malheiro and collaborators(13), the implementation of monitors with SB who were experts in self-management (lay led) was considered not only an important learning strategy, but also a motivational strategy, associated with the perspective of, in the future, managing their condition autonomously and also because the possibility of becoming lay leaders themselves in the future summer camp. Similarly, the mentorship regimen was also emphasized by the youths. They considered the mentorship regimen valuable, because it obligated them to improve their self-care performance and the management of their condition, so that they could transmit this information correctly to the younger participants. Even though the results corroborate the benefits of using role models with the same condition and self-management experts to develop these skills among young individuals with SB, this technique is underexplored by the scientific community.

CONCLUSÃO

The training camp yielded surprising results. The results were unanimous in indicating the importance of the training program for developing self-management skills amongst adolescents with SB, which are for these youths to achieve autonomy. The benefits relative to the psychoeducational intervention strategies used in the program (problem solving, role-playing, plan of action, and modeling) were clearly demonstrated and can be associated with the significant improvement in self-management behaviors.

The changes observed in the youths on taking on the role of mentors point to the effectiveness of this strategy and its potential for children with chronic conditions/disabilities. Furthermore, the existence of lay led role models with SB was a key factor to facilitate the learning process, given that these people, having experienced the same difficulties as the youths, can provide them with better strategies for overcoming them. These results support the evidence that lay led programs are beneficial to youths.

The results of this study can help underpin changes in practices relative to the issue of promoting self-management skills among youths with chronic conditions and facilitating their transition to adulthood. Thus, the adaptation of the Expert Patients Program for self-management education to the pediatric SB population was successful and the results point to its effectiveness.

The present study is an important scientific and innovative contribution to nursing in the field of youths with special healthcare needs within the scope of health promotion and the prevention of secondary conditions. The program was an important mark in the development of the youths' mastery over their condition, facilitating transition into adulthood and, consequently, improving their quality of life in terms of health and well-being.

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