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BUILDING RESILIENCE AMONG ADOLESCENTS WITH CANCER: A CASE STUDY

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ABSTRACT. The aim of this study was to evaluate the efficiency of a psycho-educational program to increase resilience in the case of an adolescent diagnosed with cancer. The program incorporates the cognitive-behavioral principles and resilience protective factors of adolescents with cancer. The program consisted of six individual meetings based on the information provided by a booklet specially designed for this project. The efficiency of the program was assessed by evaluating the protective factors at the beginning of the program, at the end of it and at a 1 month follow-up. Also, the opinions of the participant involved in this study were assessed by a questionnaire with open questions.

The results showed that there was an increase in scores on effective coping strategies and perceived social support. Depression scores remained at a low level throughout the study and anxiety and optimism scores showed an increase after the program and a decrease at follow-up. Preliminary outcomes showed changes in the desired direction. The implications of the results are discussed. Through this study we emphasize the need for development of evidence-based programs for improving quality of life in adolescents with cancer.

Keywords: *adolescent, cancer, resilience, coping, psycho-educational program*

ABSTRAKT. Das Ziel dieser Studie war es, die Effizienz eines psycho-pädagogisches Programm um die Widerstandsfähigkeit im Falle eines Jugendlichen mit Krebs diagnostiziert erhöhen zu bewerten. Das Programm beinhaltet die Kognitiv-Behavioristischen Prinzipien und Faktoren der Ausdauerschützung in Jugendlichen mit Krebs. Das Programm beinhaltet sechs verschiedene Treffen, welche sich auf den Informationen der spezifisch für diesem Programm erstellten Broschüre stützen. Die Leistungsfähigkeit des Programms wurde durch die Evaluation der Schützungsfaktoren am Anfang des Programms, am Ende dessen und nach einem Monat Nacharbeitungszeit gemessen. Die Meinungen der Jugendlichen, die an

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diesem Projekt teilgenommen haben, wurden mithilfe eines Fragebogens mit offenen Fragen beurteilt. Die hier-erfassten Resultate zeigen, dass ein Wachstum im Bereiche der effektiven Coping-Strategien und der wahrgenommenen sozialen Unterstützung bemerkbar sind. Depressions-niveau ist auf einer niedrigen Ebene durch die Studie hindurch geblieben. Bezüglich der Anxietät und des Optimismus konnte man eine Steigerung nach dem Programm bemerken, jedoch eine Senkung während der Nachfolge. Die Voruntersuchungsresultate dieser Studie zeigen Änderungen in der gewünschten Richtung. Die Implikationen dieses Resultats werden besprochen. Durch dieser Studie betonen wir die Notwendigkeit für Recherche und Entwicklung der sich auf Beweisen-stützenden Programmen für Jugendliche mit Krebs, wobei man die Entwicklungssonderheiten und deren spezielle Bedürfnisse.

Schlüsselwörter: *Jugendlicher, Krebs, Ausdauer, Bewältigungstrategie, Lernen duch Psychologie*

Introduction

Cancer in adolescence

Adolescents with cancer (AWC) have to adapt to normal developmental changes, but also to changes that occur along with the cancer diagnosis. We note that there are few studies that address the problem of resilience in AWC and even fewer studies that create and evaluate targeted programs for them. Given the complex system of the disease that can interfere with the typical development of adolescents, psycho-educational programs are needed in this particular age segment (Fernandez & Barr, 2006).

To create appropriate programs for this age group, we need to understand the complex nature of the disease, treatment and the way that teenagers react and understand these events. The cancer experience interferes with the typical challenges faced by adolescents: forming an identity and self-image, increasing autonomy as well as the development of social and romantic relationships (Blotchy & Cohen, 1985). Emotions are an important factor, as they are related to the coping strategies that adolescents use, to mental health, various behaviors and social relationships. Not all AWC react in the same way and certainly not all of them develop psychological problems, but medical conditions caused by illness create a risk background for developing psychological problems.

In their meta-analysis Ettinger and Heiney (1993), identified several problems faced by AWC: adverse effects of treatment, loss of control, problems related to body image and self-concept, family dependency, relationships with friends and pain management. Some of these problems are included among the psychosocial needs identified by us in a previous study: teenagers need information about diagnosis and treatment, management of emotions, communication with friends and family, body image management and how to cope with hospitalization periods (Vâjâean & Băban, 2014).

Resilience

Adolescents' adaptation to these situations, despite these adverse circumstances, involves the development of resilience. When we talk about resilience, there are three main characteristics we have to mention: the presence of conditions with a high level of distress, the presence of protective factors (internal and external resources), and the development a positive adaptability, despite a significant adverse experience (Garmezy, 1990; Zolkoski & Bullock, 2012). In this study, resilience refers to a dynamic process encompassing positive adaptation within the context of significant adversity (Luthar, Cicchetti & Becker, 2000). The Protective Factors Model (Garmezy, 1992) shows that the presence of protective factors can reduce the relationship between risk factors and negative results like high levels of emotional distress. In other words, resilience is inhibited by risk factors and promoted by protective factors.

Risk factors

Risk factors can be divided into two categories (Haase, 2004). The first category, illness related risks are: uncertainty about diagnostic and symptom-related distress. These factors can have negative influences on quality of life and resilience. Uncertainty is greater when the patient doesn't understand what is happening to him, or when he/she doesn't have a clear conceptualization about disease, treatment and side effects. Psychological distress increases with the uncertainty. Pain, anxiety and mood disturbance related to disease have been associated with the cancer experience, so these variables must be taken into account in an intervention which targets resilience.

The second category of factors are those related to individual risk: defensive coping. Coping refers to "the constantly changing cognitive and behavioral efforts to manage specific external/ internal demands appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984). Defensive coping are those strategies used in order to protect the self in threatening situations (Compas, Connor-Smith, Saltzman, Thomsen & Wadsworth,

2001). These strategies can create problems when they become stable over time, and when the adolescents don't develop adaptive coping strategies, so that may affect the level of resilience and quality of life (Bull & Drotar, 1991). Differences between coping strategies were associated with variability in emotional response to stressful events, so some forms of coping, such as denial or self-blame were associated with higher levels of distress (Folkman & Lazarus, 1988).

Protective factors of resilience and programs that foster them

Protective factors can be divided into three categories: individual, family and social protective factors (Haase, 2004). In this study we focus on individual protective factors, without forgetting the importance of programs that facilitate the integration of AWC in social life, or family protective factors, because family is an important source of protection from psychosocial problems.

Individual protective factors are related to coping strategies, because they are one of the important components of resilience that can be promoted. Examples of adaptive coping strategies are problem solving strategies, positive reappraisal, optimism, acceptance, looking for social support and gaining knowledge about cancer and treatment (Kyngas, et al., 2001). Amongst the protective factors there is also the self-efficacy regarding the promotion of coping strategies (Bandura, 1994). Patients with high levels of perceived self-efficacy showed a greater capability to engage in active coping strategies in order to cope better with problems related to the disease and treatment (Heitzmann, et al., 2011). There is also research showing that enhancing the positive affects increases resilience (Fredrickson, 2001) and maintains a proactive attitude. Individuals who use coping strategies trying to solve the problem instead of avoiding it have more positive affect, which leads to an increase of resilience (Vulpe & Dafinoiu, 2012).

In a review of developed interventions for adolescents with cancer (Seitz, Besier & Goldbeck, 2009), four interventions that approach different problems associated with diagnosis were evaluated. The most promising results were from a study that addresses the psychosexual problems of adolescents with cancer (Canada, Schover & Li, 2007). The program consists in education and support regarding cancer and such issues as sexual development and function. The participants from the interventions group reported increased knowledge about the effect of cancer on sexuality, improved body image, and a significant decrease in the overall level of emotional distress after the intervention.

Children who are well informed about the disease and treatment have lower levels of distress and anxiety, especially in terms of psychological distress caused by medical procedures (Jaaniste, Hayes & Von Baeyer, 2007). The

program *Coping with Cancer* Web-based Program Content (O'Conner-Von, 2009) was developed for adolescents with cancer in order to increase their level of knowledge regarding diagnosis and treatment, to lower the level of anxiety and to increase healthy coping strategies. Following the program, no significant differences in anxiety or coping were detected. On the other hand, there was a significant change in cancer knowledge.

In a study of 40 adolescents with chronic disease, the offering of information regarding coping strategies were very appreciated because these strategies are considered to be usefull by adolescents in order to efficiently addapt to desease (Kyngäs, 2003). The efficiency of the informational programs for reducing the depression and anxiety was also demonstrated for adults with cancer (Jacobs, Ross, Walker & Stockdale, 1983). Psycho-educational programs based on information about disease, treatment and specific coping strategies have been well established for other chronic diseases like diabetes (Lehmann, 1997).

Current study

The REZI (from resilience – in Romanian "**rezi**lienţă") psycho-educational program addresses the main needs of adolescents with cancer in order to increase the protective factors of resilience. The program is based on cognitive behavioral paradigm components such as: cognitive restructuring, promoting adaptive coping strategies and problem-solving strategies, acceptance, self-efficacy and on need assessment of AWC, conducted in a previous study (Vâjâean & Băban, 2014). The main topics that emerged from the analysis were information about disease and treatment, emotion management, communication with friends and family and bodily changes management. Amongst the most effective coping strategies used by AWC were cognitive reappraisal, optimism or positive thinking and the use of family as a veritable source of support, instrumental actions performed during hospitalization (reading, watching movies, internet or activities in the playroom, wearing a wig) and seeking information on the internet especially. Healthcare was not mentioned as a source of information. We noticed that AWC had weak strategies for emotion management, they often used avoidance as a coping mechanism and didn't use friends as a source of social support. Also, the results shaped a pattern of emotions, characterized by feelings of hope, but also fear, anxiety, insecurity or sadness (Vâjâean & Băban, 2014).

Based on literature (Haase, 2004; Bull & Drotar, 1991) and on the results from need assessment, we developed a psycho-educational booklet for teens with cancer. The main themes of the booklet were: general information about cancer and treatment, emotions and thoughts about cancer, communication with friends and family, time spent in the hospital and bodily changes. Each chapter from the

booklet was discussed in an individual meeting with the patient. This study does not intend to validate a protocol for intervention in cancer. Our objective was to evaluate the validity of the program developed around the needs of adolescents with cancer by applying it to one pilot study.

Methods

Objective: The aim of this study was to evaluate the efficiency of a psycho-educational program to increase resilience in the case of an adolescent diagnosed with cancer.

Case description

The participant from this study, M.M, is a 15 year old girl, a high school student, diagnosed with Undifferentiated Nasopharyngeal Carcinoma. The main treatments were chemotherapy and radiotherapy. Parents provided written consent for the adolescent. The study was approved by the Ethics Committee of Babes-Bolyai University and by the Institute of Oncology "Dr. Ion Chiricuţă", Cluj-Napoca, Romania.

The program is structured on four individual meetings where the information from the booklet is discussed and followed by one last meeting. Questionnaires that evaluate protective factors of resilience were applied before the program (baseline), after the program (the evaluation of program effectiveness) and on the follow-up meeting after 1 month of completing the program. Also at the last meeting of the program, the participant provided feedback on the usefulness of the information provided by the booklet and also on the strengths and weaknesses of the program.

Each meeting aims to clarify the information contained in the booklet and to identify possible barriers that teens face when they use this information. Self-efficacy is a very important aspect of this program. Through the process of vicarious coping, some examples of teenagers who went through the same situation are discussed and various ways of dealing with stressful situations are illustrated by role-play. Through the self-monitoring process, the adolescent assess their emotions, behaviors and changes that occur during the program (by using a diary). Similarly, through the process of social persuasion the counselor encourages the patient and provides feedback within a framework of acceptance, empathy and non-directive speech.

In the first meeting general information about the patient was discussed, the assessment instruments were completed, and also first information about the significance of the cancer disease and treatments was introduced. At this point, M. knew the diagnosis, following the beginning of treatment in the shortest time. This moment was marked by both uncertainty about the future, as well as by relief, because until then, the adolescent didn't know exactly what was happening with her and why she had certain physical symptoms.

In the second meeting, the main elements of cognitive behavioral theory were discussed. We wanted the adolescent to understand the A-B-C model (Ellis, 2001) or the connection between events, thoughts and emotions. Also, we addressed specific emotions such as anxiety or sadness and specific emotion regulation strategies. An example of exercise in this chapter refers to how AWC can cope with various concerns. The exercise is called The Worry Solution (Butler & Hope, 2007), under the motto: *If worrying makes you do something, it is useful, otherwise worry is pointless.* The teenager is directed to answer three questions: What am I worrying about? Is there anything I can do about this? Is there anything I can do right now? Based on these questions specific problem solving strategies are constructed. These thoughts and emotions can be customized on the adolescent life situations. In the case of M., most examples illustrate possible situations from school or the treatment: *I worry that the radiotherapy mask will tighten on me*, or *I worry that colleagues from school will laugh at me*.

The third meeting addressed the bodily changes that may occur as effects of treatments. A negative body image is often associated with avoidance of social situations and feelings of depression and anxiety (Pendley, Dahlquist & Dreyer, 1997). Together with the adolescent, we made a plan of action before the hair started to fall. The transition was easier when the hair was cut short. During the treatment, the teenage wore a wig to deal with the moment when she met her friends. Also, irrational thoughts about body image were modified according to the cognitive behavioral paradigm. The discussions based on the information from this chapter tried to reduce the emotional impact of hair loss and to develop an action plan to promote a sense of control.

The fourth meeting addressed the topic of communication between the adolescent and family, respectively friends. During the meeting we discussed strategies that facilitated the integration of the adolescent in the group of colleagues and friends from school. Strategies based on assertive communication to improve family relationships were also discussed, especially with the parent who remained with the teenager during hospitalization.

The fifth meeting was built on distraction components that form the acronym *ACCEPTS - activities, contributing, comparisons, emotions, pushing away, thoughts and sensations* (Linehan, 1993). Those components had the role of promoting distress tolerance, developing the ability to accept the negative affect and situations and promoting problem-solving strategies. Also in this meeting, the guided imagery relaxation technique was learned (Baider, Uziely & Kaplan De-Nour, 1994), in which M.M learned to relax by imagining that she is in her room. M.M considered that this scenario was the most appropriate for her.

During **the follow-up meeting** the main information from the meetings was reviewed. Also concerns regarding the first day of school have been discussed, which M.M considered them the most important problem. Through role-playing, M.M practiced applying communication and coping strategies and other coping strategies, learnt in chapter four, with colleagues at school.

Measurements

Distress, the level of anxiety and depression, were measured using the HADS scale - Hospital Anxiety and Depression scale (Zigmond & Snaith, 1983), Romanian version (Ladea, 2005). HADS, which consists of two subscales, one for symptoms of anxiety (HADS-A) and one for symptoms of depression (HADS-D) use subscale scores ranging from 0 to 7, indicating normal distress, from 8 to 10, indicating low distress and 11 to 14 indicating maximum distress. This scale has been adapted to the Romanian population (Ladea, 2005).

Optimism, defined as disposition or tendency to see events in a favorable manner, was measured using the LOT-R scale - Life Orientation Test (Scheier, Carver & Bridges, 1994), (Băban, 1998). The scale contains 10 items, listed on a 5-point Likert scale, where 0 means "strongly disagree" and 4 means "strongly agree". Items 2, 5, 6, and 8 are fillers and high values imply optimism. This scale has been adapted to the Romanian population (Băban, 1998)

Perceived social support was measured using Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988). This scale is suitable for teenagers due to the inclusion of items that refer to family, friends and significant others. The scale contains 12 items, on a 7-point Likert scale, where 1 means "strongly disagree" and 7 means "strongly agree". This scale has been adapted to the Romanian population (Marcu & Podea, 2013)

Coping Self-efficacy is the ability to perform certain behaviors to manage or cope with disease and related treatments. In order to measure self-efficacy the CBI scale was used - The Behavior Inventory Cancer brief form (Heitzmann et al., 2001). The scale covers seven major areas in which adolescents must develop self-efficacy, namely: (i) the maintenance activity and independence; (ii) searching and understanding medical information; (iii) stress management;

(iv) adaptation to the adverse effects of treatment; (v) the acceptance of the disease and maintaining a positive attitude; (vi) emotion regulation; (vii) social support. The scale contains 14 items, on a 9-point Likert scale, where 1 means "not at all confident", 5 means "medium confidence" and 9 means "very confident". This scale has been adapted to the Romanian population (Mereuta & Craciun, 2009).

Satisfaction with the program was measured through the following questions, on a 5-point Likert scale, where 1 means "not at all" and 5 means "very much": "how helpful did you find the information from the booklet?"; "how much did the information from the booklet help you understand your situation?"; "how much did the information from the booklet help you understand your emotions?"; "how much did the information from the booklet help you communicate with your friends and family?"; "how much did the information from the booklet help you adapt to bodily changes?"; "how much did the information from the booklet help you pass through hospitalization periods more easily?"

Strengths and weaknesses of the program were measured through the following open questions for each chapter from the booklet: "please mention one thing you liked in this chapter"; "please mention one thing you would like to improve in this chapter".

Results

At the baseline, M.M obtained a score of 10 on the anxiety scale (HADS-A), which is considered a low level of distress; a score of 8 on the depression scale (HADS-D), which is considered a normal level of distress. After the program, M.M obtained a score of 14 on the anxiety scale, which is considered a high level of distress and a score of 7 to the depression scale. Also, at the follow-up assessment, M.M obtained a score of 6 on the anxiety scale and a score of 9 on the depression scale (Fig.1 and Fig.2).

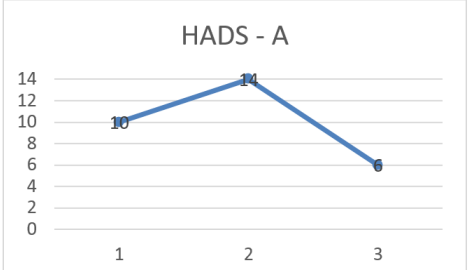

Fig. 1. Anxiety scores in the three moments of the study: baseline (T1), after the program (T2) and follow-up (T3)

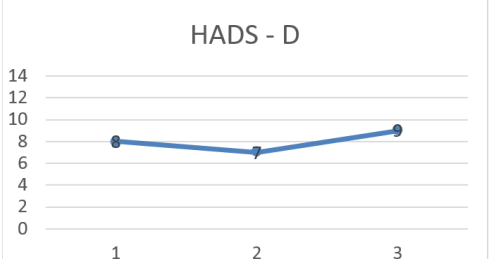

Fig. 2. Depression scores in the three moments of the study: baseline (T1), after the program (T2) and follow-up (T3)

Specific cut-off scores and population norms have not been established for coping self-efficacy scale, a total coping efficacy score is calculated by summing the scale scores. High scores (124) reflect stronger self-efficacy. At the baseline, M.M obtained a score of 91 on this scale. After the program, M.M obtained a score of 107 and at the follow-up assessment, M.M obtained a score of 120 (Fig.3).

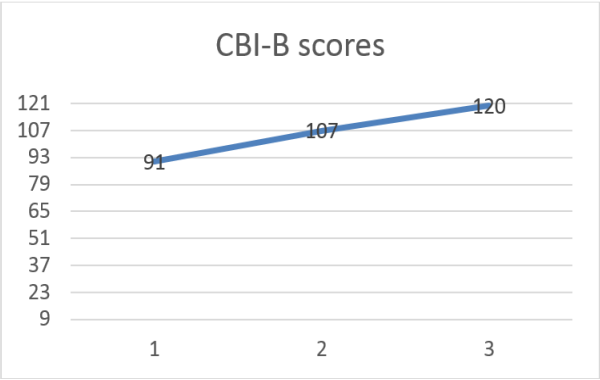

Fig. 3. Coping self-efficacy scores in the three moments of the study: baseline (T1), after the program (T2) and follow-up (T3)

Optimism score ranges from 0 to 24 and high values imply optimism. At the baseline, M.M obtained a score of 18 on this scale. After the program, M.M obtained a score of 12 and at the follow-up assessment, M.M obtained a score of 18 (Fig.4).

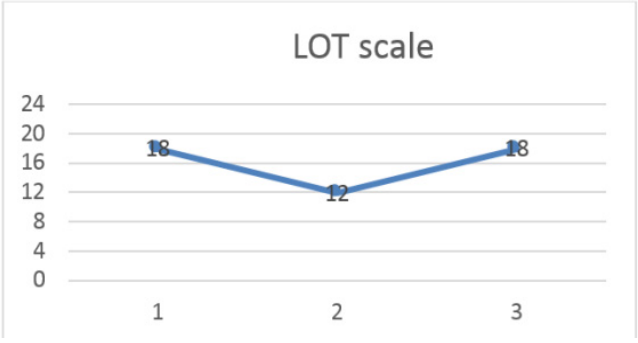

Fig.4. Optimism scores in the three moments of the study: baseline (T1), after the program (T2) and follow-up (T3)

Perceived social support scores ranges from 0 to 24 and high values imply a high perceived level of social support. We were interested in two subscales of this scale, perceived social support from the family and from friends. At the baseline, M.M obtained a score of 18 for family social support, and 5 for friend's social support. After the program, M.M obtained a score of 20 for family social support, and 11 for friend's social support. At the follow-up assessment, M.M obtained a score of 20 for family social support, and 13 for friend's social support (Fig. 5 and Fig. 6).

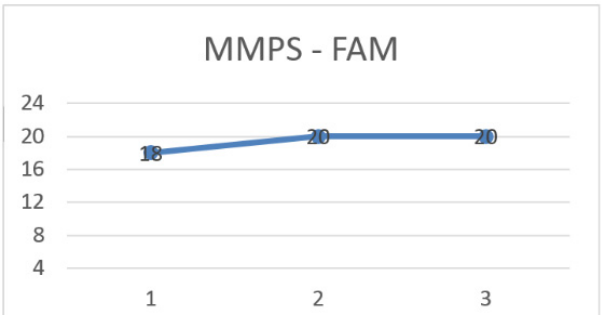

Fig. 5. Perceived family social support scores in the three moments of the study: baseline, after the program, and follow-up

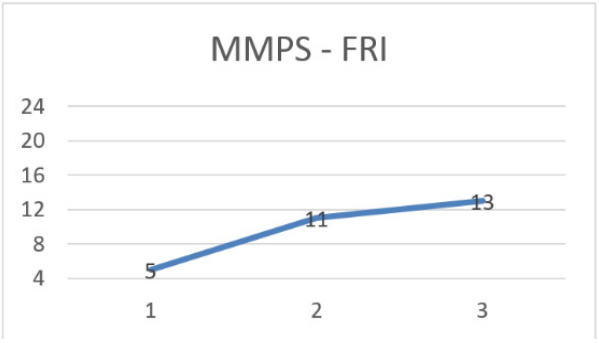

Fig. 6. Perceived friends social support scores in the three moments of the study: baseline, after the program, and follow-up

In terms of *satisfaction with the program*, M.M believed that the information presented in the booklet were very useful in understanding the disease, current emotions and bodily changes. Also, the information presented partially helped her to communicate more efficiently with her friends and family. In terms of improved points for the presented material, M.M considers that more

examples of teenagers who went through the same situation would be useful. According to her, it would be useful to know that she is not the only one who passes through such situations and also to find ways to solve various problems that arise during treatment (ex: how to cope with the situation in which the radiotherapy mask tightens its grip on me, etc.).

"I would add more opinions of teenagers that pass through this situation."

She also considers that it would be useful to have more information regarding communication with the family and more activities to occupy their time spent in hospital.

"I would like to find more tips on how to communicate with my family."

Discussion

AWC have special psychological needs, which should be addressed in programs specifically developed for this age and situation. The REZI psycho-educational program is based on cognitive behavioral paradigm components, cognitive restructuring, promoting adaptive coping strategies and problem-solving strategies, acceptance, self-efficacy. These protective factors minimize the impact of risk factors and promote resilience. The REZI Program is structured on five individual meetings and a follow-up meeting, where the information from the psycho-educational booklet developed for this program is discussed. This program was tested on a single patient. Because it proved to help this single case, Future studies should test this program on a larger sample of patients. It is also necessary in future studies to include a control group to see if its protective factors changes are the result of the program or other factors. Protective factors of resilience were evaluated in the three moments of the study. Future research should evaluate the protective factors of resilience with multiple measurements, in the three stages of the study.

In this study, there was an increase in scores in terms of effective coping strategies and perceived social support. Depression levels remained at a low level throughout the study. In terms of anxiety and optimism, scores show an increase after the program and a decrease on the follow-up. This trend may have several explanations. First, the program started alongside the initiation of treatment, when, according to the grief process (Engel, 1962) the patient may pass through a period of shock, denial and disbelief (Axelrod, 2006). The next stage on this process is characterized by anxiety, depression and anger, and the final stage is characterized by resolution and acceptance. These processes can interfere with the effectiveness of the program. Also, treatments can influence the emotional state of the patient, which can interfere with the psycho-educational program process. In the case of adolescent “M.M.” the treatment process could interfere

with the effectiveness of the program. More precisely, at the end of the program the pacient had finished the chemotherapy treatment, but began the radiotherapy treatment. Challenges associated with this treatment are different from those associated with chemotherapy. During the program, the patient had learned to face challenges like loss of hair, but the radiotherapy treatment was associated with new ones which could have impacted the level of anxiety. To improve the REZI program there is need for adolescents to learn to adapt to emotional problems especially, not just the practical ones. More precisely, we consider necessary that the program should focus more on cognitions behind emotional problems in order to be able to apply these cognitive strategies to a wider range of situations.

According to qualitative information, the adolescent involved in the study considers that offering examples of adolescents that passed through these health problems successfully would help in the process of disease addaptation.According to Bandura's theory (1994), one of the most important sources of self-efficacy is vicariant learning, so we suggest that programs destined for adolescents with cancer contain a series of examples of adolescents that efficiently adapted to disease. Other than these examples, we underline the importance of offering age specific activities that adolescents can practice during hospitalization Within the institution where the study took place, the activities are held especially for children with cancer, and recently, the Little People Association (For more information please access*: http://www.thelittlepeople.ro/*) prepared a special room dedicated to adolescents with cancer. In the case of patient M.M., she refused to participate in group activities, preferring to engage in different activities alone, which were more matching to her health state and hospital conditions. Future programs could offer a series of activity examples that can be shaped to the needs of adolescents with cancer, from a medical point of view as well as age appropriate.

Preliminary outcome from this study data show changes in the desired direction (e.g. increased effective coping strategies, perceived social support and optimism). An evidence based intervention that help AWC to cope better with the cancer challenges during the early phases of the treatment would represent an important step in the services provided to these patients. Through this study we emphasize the need for development of evidence-based programs for adolescents with cancer, taking into account the particularities and their special needs.

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