

Andrzej Lis-Kujawski, Beata Antoszevska, Ewa Kujawska-Lis

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ANDRZEJ LIS-KUJAWSKI
BEATA ANTOSZEWSKA
EWA KUJAWSKA-LIS

THE “SUN AND ADVENTURE” PROJECT – A CHANCE TO BUILD QUALITY OF LIFE IN CHILDREN CANCER SURVIVORS

1. Introduction

1.1. Children with cancer and quality of life

Cancer may affect children of any age group. Although data concerning morbidity are not optimistic – indicating that each year about 1300 new cases are noted, advances in treatment allow young patients to view their future with more hope than before. The latest reports indicate that the majority of neoplastic diseases in children has become curable. In some types of cancer the success rate amounts to 80%, and there are also those for which this rate reaches 95%¹. Progress in cancer treatment for children has been possible due to the acquiring more knowledge concerning the pathophysiology of this disease, and progress in fundamental science and diagnostics².

With respect to cancer, the consequences of the disease itself and its treatment (for example, chemotherapy, radiotherapy, surgical intervention) are less optimistic, in particular with reference to the three mentioned, interrelated dimensions: organic, psychological and social. Children with acute lymphoblastic leukaemia or non-Hodgkin lymphoma are at risk from the consequences of chemotherapy, frequent lumbar punctures and bone marrow biopsies. In some patients, preventive and prophylactic radiotherapy of the central nervous

ANDRZEJ LIS-KUJAWSKI, psycholog terapeuta, doktor nauk humanistycznych, Katedra Psychologii Rozwoju i Edukacji, UWM Olsztyn; e-mail: foxandy@wp.pl

BEATA ANTOSZEWSKA, pedagog, doktor nauk humanistycznych, Katedra Pedagogiki Specjalnej, UWM Olsztyn; e-mail: beata.antoszevska@wp.pl

EWA KUJAWSKA-LIS, doktor habilitowany nauk humanistycznych, Katedra Filologii Angielskiej, UWM Olsztyn, koordynator projektu „Sun and Adventure”; e-mail: ewalisk@wp.pl

¹ A. Chybicka, *Wstęp* [Introduction], w: *Od objawu do nowotworu. Wczesne rozpoznanie chorób nowotworowych u dzieci*, red. A. Chybicka, Wrocław 2009, s. VII–IX.

² M. Samardakiewicz, *Zasady wspomagania biopsychospołecznego dzieci z chorobą nowotworową*, w: *Onkohematologia dziecięca – co nowego?*, red. J.R. Kowalczyk, Wrocław 2009, s. 144–162.

system needs to be introduced, which is usually further burdened with additional consequences for the organism. Children suffering from Hodgkin's lymphoma, apart from chemotherapy and radiotherapy, need to undergo biopsies on the involved lymph nodes. In the case of bone cancers, apart from intensive chemotherapy, surgical removals of the involved bones are carried out, and occasionally amputation of the involved extremity is necessary³.

Changes resulting from the disease process may affect various organs and their severity may also be varied. They are most frequently associated with the type of disease, its advancement, specificity of the implemented treatment and the child's age⁴. Among the physical consequences, one may differentiate between those that are visible already during the undertaken therapy (e.g., side effects of treatment: loss of hair, excessive hair growth all over the body, vision disturbances, obesity, etc.) and those that are invisible (e.g., damage to the internal organs, infertility, disturbances in renal function, etc.).

Not only therapy itself, but also its duration and place generate specific experiences in ill children (painful medical interventions, examinations, fear with respect to the hitherto unknown hospital environment, etc.). The period of being ill and intensive treatment carried out usually in hospital conditions are associated with an extensive deprivation of the majority of psychological needs and leave their stamp on the later life of a human being⁵. Social consequences can be experienced by a child during treatment. Such are associated with a periodic or permanent change in the child's social roles. Irregular school attendance due to hospitalizations and undertaken therapy (including ill effects of treatment) may limit the possibilities of achieving success at school⁶, and further influence the choice of a professional career in the future. Moreover, some cancer survivors exhibit problems with social adaptation long after treatment, due to scars and changes in their appearances⁷.

Stanisława Zdebska et al.⁸ indicate that negative social reactions to cancer survivors and their consequent feelings of rejection and distrustfulness generate their awareness of being different, thus deforming their way of thinking and impacting their decisions regarding the future. Children's attempts to return to "normal" life after cancer treatment are long-lasting and frequently difficult.

Many authors who deal with the functioning of cancer survivors indicate that the social environment plays a crucial role in the healing process

³ M. Samardakiewicz, J.R. Kowalczyk, *Dziecko z chorobą nowotworową*, Warszawa 1998.

⁴ J. Stefanowicz, T. Stachowicz-Stencel, D. Sierota, E. Adamkiewicz-Drożyńska, E. Bień, K. Połczyńska, A. Szolkiewicz, A. Synakiewicz, D. Birkholz, A. Balcerska, *Z jakimi odległymi następstwami terapii przeciwnowotworowej można się spotkać u pacjentów wyleczonych z chorobą nowotworową?*, „Współczesna Onkologia” 2009, nr 13(4), s. 206–211.

⁵ W. Pilecka, *Choroby nowotworowe*, w: *Psychologia zdrowia dzieci i młodzieży*, red. W. Pilecka, Kraków 2011, s. 304–315.

⁶ M.S. Sanger, D.R. Copeland, *Psychosocial Issues*, w: *Handbook of Pediatric Oncology*, red. R.A. Gottlieb, D. Pinkel, Boston 1989, s. 196–214.

⁷ M. Samardakiewicz, J.R. Kowalczyk, *Dziecko z chorobą nowotworową...*

⁸ S. Zdebska, J. Armata, W. Balwierz, M. Hnatko-Kończak, *Ocena i perspektywy psychosocjalnej adaptacji dziecka z chorobą nowotworową*, „Pediatria Polska” 1991, nr LXVI, s.132–136.

of children treated for cancer⁹, and that the life of ill children during treatment and after its completion should not differ from that of other, healthy people. For the functioning of a child treated for cancer it is significant that the negative consequences of treatment are diagnosed as early as possible and the rehabilitative process should be properly and systematically conducted¹⁰. Rehabilitative activities should encompass both individual and group procedures that are adequate to the individual possibilities and needs of a child. The following types of rehabilitation can be differentiated: physical, vision, hearing, speech or educational therapy¹¹. The return of children and youth after cancer treatment to various activities that they enjoyed before diagnosis depends on complex, comprehensive, specialist corrective and therapeutic activities. Sensitivity to problems that children may experience, assessment of their psychological condition (at the moment of getting ill) and its monitoring, as well as close cooperation with the family and school environments facilitate adequate support.

A growing interest in quality of life of children treated for cancer implies focusing not only on the process of treatment itself, but also on the period after treatment completion¹². Not only curing the child in the medical sense – so significant at the moment of cancer diagnosis – is important, but also the quality of life following treatment completion. Even before cancer therapy is implemented, one of the tasks of medical teams is to analyze potential "profits" and "losses" resulting from the implemented treatment methods. Such an in-depth assessment serves to protect a child from the negative consequences of the implemented therapy or to minimize them. Many scientific associations indicate a need for a long-term monitoring of the condition of children cured from cancer¹³. This is justified by the fact that children with chronic somatic diseases should be treated as a risk group as regards adaptive problems, especially in terms of emotional functioning, self-esteem, social adaptation, relationships with peers and school performance¹⁴. Consequently, children after cancer treatment should receive comprehensive support, facilitating the achievement of the level of functioning typical of their healthy peers.

Activities addressed to children after cancer treatment are based on the concept of "the truly cured child" as created and defined by van Eys¹⁵. This concept encompasses in a comprehensive way treatment and the consequences

⁹ Tamże.

¹⁰ J. Stefanowicz i in., *Z jakimi odległymi następstwami terapii przeciwnowotworowej...*, s. 206–211.

¹¹ J. Korzeniewska, *Opieka psychologiczna i rehabilitacyjna nad dziećmi i młodzieżą po kompleksowym leczeniu onkologicznym z powodu guza mózgu*, „Psychoonkologia” 2004, nr 7(3), s. 87–89.

¹² J.R. Kowalczyk, M. Samardakiewicz, *Rekomendacje dotyczące opieki psychospołecznej nad dziećmi z chorobami wyleczonymi*, „Pediatria Polska” 2000, nr LXXV (9), s. 729–736.

¹³ M. Samardakiewicz, J.R. Kowalczyk, *Dziecko z chorobą nowotworową...*

¹⁴ W. Pilecka, *Przewlekła choroba somatyczna w życiu i rozwoju dziecka. Problemy psychologiczne*, Kraków 2002.

¹⁵ J. van Eys, *The truly cured child?*, „Pediatrician” 1991, nr 18(1), s. 90–95.

of the disease and therapy. According to this scholar, a child is fully cured when this child's somatic, psychological and social functioning is not significantly different from the functioning of healthy peers. In other words, this concept denotes a child who is on par with healthy peers in development, maturation, achievement, and aspirations. Stages leading to a truly cured disease are as follows: eliminating the symptoms of a disease (a biological cure), then eliminating psychological outcomes (a psychological cure) and, finally, social consequences of a disease (a social cure). Van Eys believed that school reintegration is the primary method by which psychosocial cure is approached and achieved. The elimination of medical and psychological consequences for each disease is always the basic priority for any therapy. As a result of focusing on medical aims and frequently found economical limitations, eliminating the social consequences of a disease becomes that stage which is not treated with proper attention; whereas this is an important aim that should also be achieved when considering and creating a child's permanent psychosocial well-being.

When analyzing the attempts to eliminate the social consequences of a disease the concept of "quality of life" is most useful, as it allows researchers to examine and monitor the level of one's well-being and those conditions leading to it. The notion of "quality of life" has no one generally accepted definition. As observed by Christine Eiser, "The scientific study of QOL [quality of life] is complicated by the popular and everyday uses of the term"¹⁶. Jakub Trzebiatowski¹⁷ stresses that here are many "qualities of life." When reviewing various approaches to the issue of quality of life in children treated for cancer, Christine Eiser emphasises the inadequacy of general notions in paediatric medicine, such as the equation of quality of life with physical symptoms, that is if a child is severely ill then that child's quality of life is low¹⁸. In social sciences quality of life is generally treated in terms of such categories as: proper satisfaction of one's needs, subjective well-being or positive experiences. However, if one wants to measure the quality of life of individuals after a long-term cancer therapy obviously related to a great extent to health condition and well-being, it is suitable to refer to the understanding of the quality of life as developed by medical sciences. One of the attempts at formulating a uniform definition of "Health Related Quality of Life" (HRQOL) was undertaken by Schipper et al. who defined it as "The **functional effects of a disease and its following therapeutic effect** on a **patient** as it is **experienced** by the **patient**"¹⁹. The HRQOL definition accounts for the four basic functional aspects of the patient – physical condition and mobility, psychological condition, social and economic conditions and somatic experiences. Over the years, quality of life measures focused specifically on cancer patients have been developed. These

¹⁶ J. Trzebiatowski, *Jakość życia w perspektywie nauk społecznych i medycznych – systematyzacja ujęć definicyjnych*, „Hygeia Public Health” 2011, nr 46(1), s. 25–31.

¹⁷ Tamże.

¹⁸ Ch. Eiser, *Children with Cancer: The Quality of Life*, Taylor & Francis e-Library 2008.

¹⁹ H. Schipper, *Quality of life: Principles of the clinical paradigm*, „Journal of Psychosocial Oncology” 1990, nr 8(23), s. 171–185.

gradually have begun to include various domains, such as: physical, social, psychosocial, cognitive and treatment-related measures²⁰. If in 1985 Lansky et al.²¹ assessed only the physical domain, a decade later, in 1998, Varni et al.²² and Eiser et al.²³ recognized the importance of all the enumerated domains while assessing quality of life in cancer patients. Presently, the majority of definitions acknowledge the multidimensionality of the concept of quality of life and the fact that a disease affects not only the child but also the family and is subject to change: quality of life is a dynamic process that can be influenced by a variety of factors.

When discussing the quality of life of children treated for cancer several factors that may be potentially influential come to the fore: lengthy treatments, limited or no opportunities to participate in normal age-related activities, as well as the emotional concern related to a life-threatening disease²⁴. Additionally, unlike adult patients, children as a result of prolonged cancer treatment may develop a very close relationship with the parent. Occasionally such a relationship may become damaging for the child and the cancer survivor may have difficulties with forming other relationships or in becoming independent²⁵. All these factors must be considered when attempting to build quality of life for children cured from cancer. In cancer survivors, it is important to minimize subjectively felt effects of the disease and its treatment. Activities that can contribute to achieving such an effect should be well-designed and affect possibly the largest number of domains that are currently assessed as relating to quality of life.

1.2. Diving as a form of rehabilitation

Scuba diving is commonly associated with the requirements for perfect health, long-lasting training and considerable expenses. Such associations are definitely not erroneous, yet recently various attempts to employ diving as a recreational activity and also as an activity contributing to a higher quality of life have been observed.

Since 1999, thanks to the activities and projects undertaken by the Polish branch of the Handicapped Scuba Association (HSA), it has become possible for people with disabilities to experience scuba diving. Diving has become a more accessible form of an activity that has features of comprehensive rehabilitation. Scuba diving combines elements of physical therapy and social rehabilitation, whilst being practised in a natural environment, thus triggering

²⁰ Ch. Eiser, *Children with Cancer...*

²¹ L.L. Lansky, M.A. List, S.B. Lansky, M.E. Cohen, L.F. Sinks, *Toward the development of a play performance scale for children (PPSC)*, „Cancer” 1985, nr 1(56), s. 1837–1840.

²² J.W. Varni, E.R. Katz, M. Seid, D.J.L. Quiggins & A. Friedman-Bender, *The pediatric cancer quality of life inventory-32 (PCQL-32)*, „Cancer” 1998, nr 82, s. 1184–1196.

²³ Ch. Eiser, *Children with Cancer...*

²⁴ Tamże.

²⁵ Tamże.

great involvement²⁶. Relatively recently a new phenomenon has appeared – projects aiming at the employment of various outdoor activities, such as diving, in order to improve the participants' self-esteem and quality of life. This can be exemplified by the project called “Sun and Adventure” which is primarily dedicated to children following cancer treatment.

1.3. Project Outline

The “Sun and Adventure” Project aims at supporting children in efforts to eliminate the social consequences of cancer and its lengthy treatment. This is achieved via teaching cancer survivors (that is children biologically cured, with no medical symptoms) to swim and scuba dive during a summer camp organized in Croatia. Owing to its climate, the Croatian coast is an adequate location for a camp in which children spend most of their time in the water. The location for a camp must be chosen carefully for cancer survivors due to their lowered immunity. Moreover, a location away from the children's place of residence is chosen to assist children in developing a healthy relationship with their parents – that is a gradual separation from them and a learning to form new relationships with others. This is one of the major aims within the social and psychosocial domains contributing to their quality of life. The physical domain is obviously catered to by means of various activities that cancer survivors could not have participated in during their therapies.

Experiences gathered during the previous editions of the Project were encouraging and motivating in the decision to organize another camp. This report presents psychological observations obtained during the 5th edition of the Project in 2012.

The participants of the camp included seven children, aged 11–14 years – 5 cancer survivors treated for **acute lymphoblastic leukemia** (ALL) and 2 with cerebral palsy (included in the program to provide cancer survivors with a different perspective on their disease by demonstrating to them other problems experienced by physically disabled children). This report concerns only cancer survivors. The minimum age was set at 11 years for a variety of reasons. First, younger children would find it extremely difficult to leave their parents for a two-week camp organized abroad. For such young cancer survivors the camp might be emotionally too difficult to handle since one of the consequences of cancer treatment includes the very close relationship with the caretaker and severing such at this young age might be potentially damaging. Second, children are expected to learn to be independent, especially during self-service and swimming activities, thus again younger children might find it too difficult.

²⁶ E. Kujawska-Lis, A. Lis-Kujawski, *Nurkowanie jako forma terapii i rekreacji osób z niepełnosprawnościami nabytą*, w: *Aktywność ruchowa osób niepełnosprawnych*, red. J. Migasiewicz, E. Bolach, t. 3, Wrocław 2008, s. 233–241; A. Lis-Kujawski, *Na dnie ale szczęśliwi. Nauka nurkowania jako możliwość podnoszenia jakości życia dzieci po chorobie nowotworowej*, w: *Dziecko przewlekłe chore – problemy medyczne, psychologiczne i pedagogiczne*, red. B. Antoszevska, Toruń 2011, s. 123–136.

And finally, as observed by Eiser²⁷, there are methodological limitations to measure quality of life in younger children, especially those below 8 years of age; thus in order to gather some psychological data older children were selected.

2. Materials and methods

2.1. Research group

The group of cancer survivors consisted of 4 boys ([A] and [B] – 12 years old, [C] – 11 years old, [D] 13 years old) and one girl ([E] – 14 years old). All children in this group were treated with chemotherapy, most of them with radiotherapy, and in single cases the removal of mediastinal tumour (E) and hematopoietic stem cell transplantation (HSCT) (A). The total hospitalization time due to treatment ranged from 8 to 36 months; the average time of all hospitalizations for individual participants amounted to 17 months. Presently the children report for follow up visits with the frequency ranging from once a year to once a month, depending on the period since treatment completion. The parents of all participants consented in writing for the inclusion in the research.

Due to the experimental nature of the Project, the participants were selected purposely in cooperation with the hospital, whereas the major inclusion criteria were the present health condition of the child, age and both the child's and the parents' consent to participate in the camp. The organizers of the Project did not have a direct influence on selecting the participants. It needs to be emphasised that originally the Project aimed at teaching the participants to scuba dive, yet it developed that none of the selected children could swim. This can be treated as a direct deficit caused by lengthy treatment, one that differentiated cancer survivors from healthy peers. This deficit forced the organizers to modify the camp program, with more emphasis being placed on learning to swim.

During the 9-day camp on the Adriatic coast, the children participated in an intensive swimming program that functioned to prepare them for their first scuba dive. After the introductory water sessions, the participants gradually learnt to use snorkelling equipment (mask, flippers, snorkel) and were able to finish their adventure with a scuba dive. Swimming activities were complemented by everyday yoga exercises as well as theatrical and arts workshops.

2.2. Research Questions

The 5th edition of the Project provided an opportunity to conduct research concerning sociotherapeutic values of the described initiative and psychosocial benefits for the Project participants. The research methods were based on the

²⁷ Ch. Eiser, *Children with Cancer...*

survey techniques, observations and interviews with the participants of the “Sun and Adventure” Project. The research aimed at assessing the efficiency of participation in the Project on the participant’s functioning, by answering the following questions:

1. What is quality of life of children participating in the Project?
2. Can participation in the “Sun and Adventure” Project increase the participant’s quality of life?
3. Can participation in the “Sun and Adventure” Project help in decreasing the level of anxiety in children?
4. Does participation in the Project lead to changes in the child’s functioning?
5. Is it possible to define the Project participants as “the truly cured children”?

2.3. Applied Research Techniques

The basic problem involved the choice of adequate measures that would be helpful in answering the research questions. The most frequently cited indicator of quality of life used for children with cancer, the Play Performance Scale for Children (PPSC)²⁸ was completely inadequate for our research for two main reasons. First, it lacks sensitivity, particularly for older children and those functioning at near normal levels²⁹, and our participants generally functioned quite well. Second, parents are asked to record their children’s activities, whereas our main aim was to assess not only physical activities, but also the functioning in other domains, particularly in the psychosocial one. The Quality of Well-Being Scale³⁰ was also inadequate. In this measure neither parents nor children make their own ratings – these are done by clinicians in four areas: physical functioning, social/ role functioning, mobility and symptoms. Since our cancer survivors had no symptoms at all (the inclusion criteria was a biological cure) this measure was rejected. Also we focused on parents’ and children’s perspectives rather than that of a clinician. A measure that involves both the ratings provided by parents and children is the Pediatric Cancer Quality of Life Inventory (PCQOL)³¹. It embraces five domains: physical functioning and treatment-related symptoms, psychological functioning, social functioning and cognitive functioning and includes a child’s form for 8- to 12-years olds and an adolescent form for 13- to 18-years-olds³². This measure accounts for both objective (physical functioning) and subjective domains (psychological functioning). The major drawback of using a specifically cancer-

²⁸ L.L. Lansky et al., *Toward the development of a play performance scale...*

²⁹ Ch. Eiser, *Children with Cancer...*

³⁰ A.S. Bradlyn, C.V. Harris, J.E. Warner, A.K. Ritchey, K. Zaboy, *An Investigation of the validity of the quality of Well-Being Scale with pediatric oncology patients*, „Health Psychology” 1993, nr 12, s. 246–250.

³¹ J.W. Varni et al., *The pediatric cancer quality of life inventory...*

³² Ch. Eiser, *Children with Cancer...*

focused inventory was that our research group combined both cancer survivors and children in a chronic condition following cerebral palsy. Additionally, the PCQOL has not been adapted for Polish users. Consequently, after much deliberation and search for an adequate measure that might be appropriate for our research group, we decided to apply a slightly modified Polish version of the Health-Related Quality of Life in Childhood Epilepsy (QOLCE) questionnaire³³. This questionnaire was designed as one of the methods for assessing quality of life of patients suffering from chronic diseases. Although originally the questionnaire is designed for patients with epilepsy, we decided to use it in our research due to its many advantages. In practice, assessment of quality of life always includes a subjective perspective of the respondent. QOLCE is exceptional in this respect – it is dedicated to children, but the ratings are done by parents, which increases the reliability of the obtained data. This measure assesses a child’s quality of life in 5 domains: physical functioning, emotional functioning, cognitive functioning, social functioning and behaviour. This questionnaire allows the researcher to measure in a unique way a child’s functioning in a number of domains embracing this functioning holistically, as well as in a multidimensional and complex way in which a disease and its consequences influence various aspects of a child’s life. The only modification introduced to the questionnaire was substituting the term “epilepsy” with “chronic disease,” thus allowing us to include all children participating in the camp. The QOLCE questionnaire was applied twice – before leaving for the camp and 4 weeks after returning from it.

The second measure applied in our research was the Polish adaptation of Spielberger’s state-trait anxiety questionnaire in the version dedicated to children STAI – C, that allowed us to measure trait and state anxiety. Altogether 3 assessments of anxiety were conducted – before the camp, and twice during the stay in Croatia: on the third and last days of stay.

The results obtained via the application of these methods were complemented by interviews conducted with the participants during the camp.

3. Results

3.1. Quality of life of children participating in the Project (5th edition)

The QOLCE questionnaire – as already mentioned – allows one to assess quality of life in children with respect to 5 domains of psychosocial functioning. Due to the introduced modification and a lack of Polish norms for different groups of patients, only an approximate assessment of the quality of life

³³ K. Mathiak, K. Karzel, K. Mathiak, P. Ostaszewski, M. Łuba, T. Wolańczyk, *Kwestionariusz Jakości Życia w Padaczkę Dziecięcej – polska adaptacja i walidacja kwestionariusza Health-Related Quality of Life In Childhood Epilepsy Questionnaire*, „Neurologia i Neurochirurgia Polska” 2007, nr 41(3), s. 203–214.

of Project participants was possible. This turned out to be surprisingly concordant with the observations of children's functioning during the camp. The questionnaire measures quality of life in a 5 point scale, where 5 is the highest possible level of functioning. The results of the questionnaire are presented in Table 1:

Table 1. Results of the initial measure of quality of life taken by QOLCE

Participant	Physical activity	Well-being	Cognitive functioning	Social functioning	Behaviour	Average score	Descriptive assessment of quality of life of a participant	Descriptive assessment of health condition of a participant
A	3.3	3.79	3.52	3.12	3.39	3.42	excellent	good
B	3.4	3.79	3.52	4.0	3.43	3.63	very good	good
C	2.8	3.21	3.43	3.0	2.69	3.03	very good	average
D	4.1	4.79	4.04	4.37	4.30	4.32	very good	excellent
E	3.5	4.18	4.79	3.0	3.92	3.88	very good	very good
Average score in the group	3.42	3.95	3.86	3.49	3.54	–		

Source: authors' own research.

The results presented in Table 1 allowed us to assess both the functioning of particular individuals and the average score in the entire group. Average total scores for particular participants ranged from 3.03 to 4.32. Referring to the 5-point scale used in the questionnaire, general quality of life in the research group can be assessed as good (3–4 range) and very good (above 4). Only one person from the group was in the range above 4. Although the differences in the questionnaire results may seem fractional, they nevertheless indicated internal differentiation within the group and pointed to those children who faced a larger number of problems. Individual variation of the participants' results within particular domains facilitates determining the type of problem.

QOLCE also allows one to compare more objective information included in specific sub-scales with a global, subjective assessment of a child's quality of life provided by the parent. In most cases the parent filling in the questionnaire rated his or her child's quality of life as "very good" and "excellent" in one case.

Based on these results, it can be concluded that the initial quality of life of the children was very good. This does not mean that such a quality of life cannot be improved upon, as evident in the average scores in specific domains. It can be readily noticed that the children's ratings were relatively lower in the domains of physical activity, behaviour and social activity. These are the most significant spheres in which quality of life of the Project participants can be potentially improved. It is also noticeable that parents tend to overestimate

their children’s quality of life – this is evidenced by an evident discrepancy between scores in particular scales of the questionnaire and a global assessment (the global assessment “very good” was expressed both in relation to children whose score in the questionnaire was 3.03 and those rated as 4.32). Discrepancies between the assessment of a child’s health condition and quality of life can be also observed (most evidently in the case of child C), demonstrating that a common evaluation of quality of life is not entirely dependent on health condition. The last observation that can be made on the basis of the questionnaire results is that in the research group quality of life did not differ significantly between children with cerebral palsy and cancer survivors.

3.2. Increasing quality of life of the Project’s participants

When the questionnaire was applied for the second time, the results obtained by each participant and the ratings for the entire group were compared to the initial scores. The second measurement was taken 4 weeks after returning from the camp. This timeframe is associated with the design of the QOLCE questionnaire that measures quality of life 4 before the actual examination. Such a period of time also allowed the parents to observe the functioning of their children following their return from the camp.

Although quality of life of children before the participation in the Project was rated as good and very good, the second measure still demonstrated positive changes. All participants achieved higher ratings in the second measure of quality of life, although in the case of children C and G the differences were minute. Based on the results, it can be assumed the most significant positive changes in quality of life occurred in the case of children B and E.

Table 2. Comparison of average scores by the QOLCE questionnaire before and after the camp

Participant	Average score before the camp	Average score after the camp
A	3.42	3.74
B	3.63	4.17
C	3.03	3.04
D	4.32	4.49
E	3.88	4.44

Source: authors’ own research.

Analogously, average scores were compared for the entire group. Only in one domain (physical activity) the result in the second measure was slightly lower than the initial result before the camp.

Based on the comparison of the measures of quality of life of the participants before and after the camp, an improvement in quality of life can be observed as measured by the QOLCE questionnaire. The most significant improvement

Table 3. Comparison of average scores of the entire group by the QOLCE questionnaire before and after the camp

QOLCE domain	Average group score before the camp	Average group score after the camp
Physical activity	3.33	3.26
Well-being	3.97	4.38
Cognitive functioning	3.99	4.16
Social functioning	3.58	4.08
Behaviour	3.52	3.87

Source: authors' own research.

Table 4. Comparison of global descriptive assessment of quality of life and health condition of the participants before and after the camp

Partici-pant	Descriptive assessment of quality of life		Descriptive assessment of health condition	
	before the camp	after the camp	before the camp	after the camp
A	excellent	very good	good	good
B	very good	very good	good	very good
C	very good	good	average	good
D	very good	excellent	excellent	excellent
E	very good	very good	very good	very good

Source: authors' own research.

was recorded for the participants B and E. Apart from the physical activity domain, the ratings of the participants in the remaining domains were higher, the most significant changes occurring in the domains of emotional well-being and behaviour. Participation in the Project can, therefore, improve the quality of life in children; however, because of the initial high level of quality of life (good or very good) the observed effect should be treated as slight or moderate in specific cases. On the other hand, it should be noted that the initial scores might have been compromised by the parents' wish for their children to be included in the Project, hence they might have rated their children higher than their actual condition might have warranted.

3.3. Participation in the Project versus anxiety level

To complement the assessment of quality of life in the researched children, anxiety levels were measured before and during the camp.

The measurement was taken by the application of the STAI-C questionnaire for children designed on the basis of the concept of anxiety developed by Spielberger. This concept clearly differentiates between anxiety understood as a state conditioned by a particular situation (state anxiety) and anxiety

Table 5. Anxiety level – trait (C2) and state (C1) in the participants before and during the camp

	Before the camp				1 measure during the camp				2 measure during the camp			
	C1		C2		C1		C2		C1		C2	
	raw score	sten score	raw score	sten score	raw score	sten score	raw score	sten score	raw score	sten score	raw score	sten score
A	37	7	36	7	20	2	21	2	20	2	22	3
B	50	9	43	8	24	4	35	7	23	4	40	8
C	27	5	51	10	46	9	56	10	54	10	59	10
D	21	3	31	6	21	3	31	6	20	2	32	6
E	20	1	24	3	20	1	23	2	20	1	23	2
	31.00		37.00		26.20		33.20		27.40		35.20	

Source: authors’ own research.

perceived as a relatively stable personality feature (trait anxiety). From the psychological perspective, the intensity of trait anxiety is most significant for the functioning of an individual. Spielberger defined trait anxiety as a characteristic or acquired behavioural disposition that makes the individual prone to perceiving a wide range of objectively non-dangerous situations as threatening and reacting to such situations with high anxiety levels disproportionate to the level of objective danger³⁴. A prospect of lowering the level of anxiety trait would be then a desirable outcome of the participation in the “Sun and Adventure” Project, as it would contribute significantly to a better functioning of the children.

The assessment results demonstrated a significant diversity in anxiety state and anxiety trait levels among the participants. In the group there were both participants with a low intensity of anxiety levels (D, E) and those in whom the values were elevated (A, B, C).

Table 6. Comparison of anxiety levels – state C1 in the participants

Participant	Before the camp	After the 3rd day of the camp	On the last day of the camp	4 weeks after the camp
A	7	2	2	5
B	9	4	4	3
C	5	9	10	3
D	3	3	2	2
E	1	1	1	1

Source: authors’ own research.

³⁴ K. Wrześniewski, T. Sosnowski, *Inwentarz stanu i cechy lęku (ISCL). Polska adaptacja STAI*, Pracownia Testów Psychologicznych PTP, Warszawa 1996.

Among the participants whose initial level of state anxiety was low, no changes were recorded in one case (E) and also in one case (D) state anxiety was further lowered. Among those children whose initial levels were elevated, in two cases state anxiety levels were lowered (A, B). In one person the level of situational anxiety was increased. Measurement taken 4 weeks after returning from the camp demonstrated the decrease in the levels of state anxiety as compared to the measurement taken before the camp.

Table 7. Comparison of trait anxiety in the participants (sten scores)

Participant	Before the camp	After the 3rd day of the camp	On the last day of the camp	4 weeks after the camp
A	7	2	3	6
B	8	7	8	5
C	10	10	10	10
D	6	6	6	4
E	3	2	2	2

Source: authors' own research.

As already mentioned, the most significant factor for the functioning of the individual is the intensity of trait anxiety because it constantly affects one's behaviour and psychological functioning. During the camp, the decrease in the levels of trait anxiety was observed in 3 participants (A, B, E). In one child this effect disappeared by the end of the camp (B), whereas the anxiety level increased in participant A by the end of the camp, yet it was still lower than the initial value. These changes were probably associated with the prospect of returning to everyday, routine functioning. In two cases (C, D) no changes in trait anxiety levels were observed during the camp. Measurement taken 4 weeks after the camp demonstrated decreased levels of trait anxiety in 4 participants.

The obtained results indicate that it is possible to decrease levels of anxiety experienced by participants of the Project. This effect was probably influenced by many factors; yet the most important outcome of the Project is the decrease in trait anxiety levels.

3.4. Changes in the child's functioning generated by participation in the Project

Evaluation conducted 4 weeks after the camp demonstrated that parents had noticed changes in the behaviour of their children. According to statements provided in the questionnaire, participant A "became more responsible," participant C "became self-confident, he believes he is allowed to do anything, he feels adult." A similar change was observed by the mother of participant E, who became "much more self-confident, more courageous, she doesn't care what

others say about her.” The parents of participant B did not notice significant changes in the behaviour of the child.

Some parents additionally noticed positive changes in the emotional well-being of their children – for instance, mother of participant C observed that after the camp “he accepted himself, he stopped being ashamed of his obesity, the scar on his chest doesn’t bother him, he is not ashamed on the beach when he takes his clothes off, he is more relaxed.” Non-specified changes occurred also in participant E (this question was answered shortly with “yes”). The parents of participant B did not record any changes in the child’s emotional well-being that might have been influenced by participation in the camp.

Answers to the questions concerning whether the camp influenced the children’s physical conditions and physical activities were similarly diversified. Ever since the camp, participant C “is willing to play football, walk, ride a bike.” A positive, yet non-specified effect was noticed by the parents of participant E. The parents of participant B did not observe such influence “because our son was always a very active child.”

The question whether the parents noticed improvement in the quality of life of their children was answered by only 2 respondents. Among these, one was positive (participant E), and one was negative (participant B).

The obtained results indicate that at least in some cases positive changes in the functioning of the children as the result of the experiences gathered during the camp are possible. It is worth noticing that positive changes occurred in those participants who more intensively experienced problems associated with self-acceptance or the reactions of others.

Assessment of the global results of the evaluation questionnaire designed for parents is difficult because not all the questionnaires were fully completed. However, all participants were satisfied with the camp. Children’s satisfaction was associated with learning a new skill if swimming (4 cases), an attempt to scuba dive (3), for one participant an independent (i.e., without parents) trip was a source of satisfaction, and for one boy – a special achievement in swimming around a peninsula (about 1.5 km) with an instructor in difficult conditions (high waves). In single cases, satisfaction was recorded with such activities as yoga, learning to stand on one’s head, shopping, trip. No remarks concerning dissatisfaction were recorded in the questionnaires. On returning, all children willingly talked about the camp, especially with family members, the majority encouraged others to see the photographs taken during the camp on Facebook.

4. Discussion

4.1. Is it possible to define the Project participants as “the truly cured children”?

In this section of discussing the outcomes of the Project the observations concerning the functioning of children after cancer treatment will be presented. Based on the concept of Van Eys, the criteria of being “truly cured” include: a lack of a subjective feeling of being ill, non-disturbed social relationships and a lack of fear associated with the potential recurrence of the disease. Based on such criteria, and with regards to the interviews conducted with the participants, two sub-groups can be differentiated.

The first sub-group consists of participants A, B and D. They believed that their lives and social relationships did not differ presently from those of their peers. They perceived themselves as well-treated by the environment and did not complain about being abused by their peers. They did not fear that their disease might recur in the future (or such opinions were very rare) and they were convinced that treatment results would be permanent. Their statements were linked by the following characteristic attitudes: “I do everything the same way [as others],” “I feel completely healthy,” “I am lucky, it was possible to cure the disease.” According to the assumed criteria, these participants could be termed as “truly cured children.”

The other sub-group consists of participants C and E. Although participant C subjectively felt completely healthy, he evidently noticed a discrepancy between himself and his peers: “I differ from them in my disease, I experienced so many things, and they different and that’s why I envy them.” This participant additionally experienced various forms of abuse associated with his appearance and disease, which significantly disturbed his social relationships and affected his mood. He also frequently feared that the disease might recur. His quality of life measured with the QOLCE questionnaire did not change; moreover all measures of his anxiety demonstrated constant maximum intensity of trait anxiety. This indicates significant adaptive problems; however, his parents noticed noteworthy changes in his functioning after the camp.

Participant E felt physically healthy; unfortunately she also experienced various forms of abuse from her peers that did not allow her to forget about her disease. Analogically to participant C, she repetitively experienced concerns about the recurrence of her disease: “only there will be this fear that I may get ill, but I don’t allow this thought.” Unlike in the case of participant C, participant E demonstrated the most significant positive change in the quality of life questionnaire and low indicators of anxiety.

This review of the results allows us to conclude that with respect to the Project participants it is possible to term some of them as truly cured children; others, however, still face various problems that are the late effects of their disease. Interestingly, it is in the case of these participants who are by no

means “truly cured,” that is in C and E, that their parents noticed significant changes with respect to increased self-confidence after the camp.

4.2. Attempt to design a model of therapeutic influence

The report of this experimental program would be insufficient without an attempt to indicate these factors which most likely influenced the participants and helped them in increasing their quality of life and in diminishing their anxiety.

Definitely, the very experience of a longer stay away from home ranks highest among the influential factors. For most Project participants the camp was their first stay abroad, and for almost all of them the first longer stay away from home without parents. As participant B recalled, the very news that he would participate in the camp was stressful for him, because he had never gone away anywhere alone. On the one hand the experience of going away alone might have been disheartening, on the other it was an opportunity to develop independence and the skill to cope in a new situation, which are important elements in the internal feeling of control.

The experience of being part of a group was also significant. In the conducted interviews all children emphasised that the awareness that all participants experienced a disease and treatment was an important group integrating factor. The participants' statement left no doubt whatsoever that the feeling of sharing the same fate and experiences helped them in establishing relationships and forming the group: “it's easier to make friends with peers who have similar experiences of a disease” (B), “they are after the same treatment as I and I feel that it's so normal with them” (C), “we have the same experiences because we had the same disease” (E). It might be argued that organizing events only for children who experienced the same disease might be limiting in allowing them to establish healthy relationships with those who do not share such experiences. We believe, however, that supporting children in making friends with peers who are in a way similar to them is the first step in assisting them in creating social contacts. Moreover, in our research group two dissimilar diseases were represented and two completely different effects (lack of disease in case of cancer survivors and physical disability in case of cerebral palsy) so children were also given a chance to establish social relationships with others, whose experiences were completely different.

An important factor that influenced positive experiences and benefits from the Project was the feeling of the achieved success associated with learning a new skill – learning to swim. Due to the physical properties of sea water, it is much easier to learn to swim in such conditions, which quickly impacted on creating a positive image of one's own physical abilities and extending one's possibilities. All children indicated learning to swim as one of the most important benefits of the camp. Another factor, apart from salty water, that facilitated achieving success was the underwater environment of the Adriatic

Sea. By providing a large number of new stimuli, it released children's natural curiosity. The achievement of success in terms of learning a new skill was closely related with the concept of quality of life as the discrepancy between what an individual can do and wants to be able to do. In most cases, the participants initially had not believed that they might be able to achieve as much as they did. This evidently improved their self-image, also in terms of comparing themselves to healthy peers – during the camp they were involved in normal age-related activities that their healthy peers practiced.

Participation in the Project was culminated with a scuba dive supervised by a diving instructor. The participants had an opportunity to experience an activity that they had perceived as inaccessible for them and difficult. Their attempts to dive fortified the stimulus of adventure and doing something exceptional as achieved through learning to swim and again allowed the participants to feel that they could do many more activities than they had once thought possible.

Learning to swim and dive also additionally helped children learn how to cope with stress under controlled circumstances, which most likely effected the decrease in the anxiety levels of the participants.

5. Conclusions

The “Sun and Adventure” Project definitely fulfilled its aims in terms of improving the quality of life of its participants and in diminishing their anxiety levels. The obtained results are relatively minor due to the high initial quality of life level of the participants. Nevertheless, participation in this program may contribute to positive changes in the functioning of cancer survivors.

In the view of future editions of the Project, it is necessary to implement more precise inclusion criteria to maximize the effects of potential positive changes. It develops that such criteria as good health condition and desire to participate in the Project are insufficient to optimally select the participants. Inviting children to participate in the “Sun and Adventure” Project should be also based on evaluation of the family environment and the financial situation of the participant, as well as the psychological consequences of cancer treatment (for example, anxiety, depression, difficulties with group adaptation).

Perhaps this Project and its effects will inspire clinicians to prescribe in the future the final prescription for their patients – large doses of sun, adventure and sea water.

**THE “SUN AND ADVENTURE” PROJECT – A CHANCE TO BUILD QUALITY
OF LIFE IN CHILDREN CANCER SURVIVORS**

SUMMARY

This paper aims at presenting the results of research carried out during the “Sun and Adventure” project dedicated for children – cancer survivors. The research focused on sociotherapeutic and psychosocial benefits for the Project’s participants. The methods involved questionnaire technique: a slightly modified Polish adaptation of QOLCE (Health-Related Quality of Life in Childhood Epilepsy) and the Polish adaptation of Spielberger’s state-trait anxiety questionnaire in the version dedicated to children STAI – C. The results were complemented by interviews carried out with the participants during the camp organized within the Project framework. Participation in the Project influenced the quality of life of the cancer survivors, although to a lesser extent than it might have been expected. The obtained results are relatively minor due to the high initial quality of life level of the participants. Nevertheless, participation in this program may contribute to positive changes in the functioning of cancer survivors.

In the view of future editions of the Project, it is necessary to implement more precise inclusion criteria to maximize the effects of potential positive changes. It appears that such criteria as good health condition and desire to participate in the Project are insufficient to optimally select the participants. Inviting children to participate in the “Sun and Adventure” Project (and similar initiatives aiming at improving quality of life) should be also based on evaluation of the family environment and the financial situation of the participant, as well as the psychological consequences of cancer treatment (for example, anxiety, depression, difficulties with group adaptation). Implications for cancer survivors are following: organized and structured camps involving physical activity and psychological assistance are profitable for young cancer survivors whose social development has been affected by their illness and treatment.

KEY WORDS: quality of life, children with cancer, cancer survivors, physical activity, sociotherapeutic activities