

## Research Article

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## Investigation of The Psychological Wellbeing after a One-Week-Skiing Intervention with Childhood Cancer Survivors

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### SUMMARY

After a child's cancer diagnosis, the life of the whole family changes immediately. Besides physical exposure due to both the disease and the treatment, psychological stress, anxiety and uncertainties arise for all family members. In a family-oriented winter sport rehabilitation camp in the alps the increased physical fitness should be focused besides the adventure and the psychological wellbeing, thus basically the path back to normality.

In order to investigate the latter, the parents of eight patients (10.87 yrs.  $\pm$  5.33 yrs.) were surveyed before and after the journey via the Strength and Difficulties Questionnaire (SDQ) consisting of 25 items divided into five subscales (social behavior, hyperactivity, emotional problems, problems with peer groups, behavioral problems).

It was pointed out that for the given setting open answer options were more meaningful than closed answers. There was only one significance for the subscale behavioral problems. However, the parents stated distinctly positive effects regarding the social togetherness of the children, the atmosphere within the families, the independence and self-confidence of the children. According to the participants the rehabilitation journey could be recommended not only for the improvement of motor parameters and physical effects, but also on a psychological level and for an increased perceived health-related life quality.

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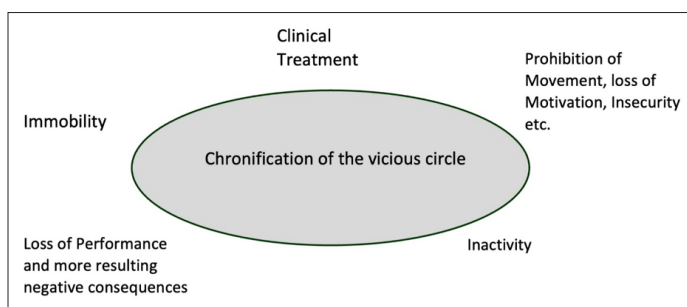
### Introduction

In the case of a child's cancer diagnosis, all of a sudden, the family life turns upside down and needs to get rearranged very quickly. This is accompanied by physical and psychological pressure for the whole family. Several studies have proven that sports and physical activity have a positive influence on the quality of life due to the increase of physical capacity and the respectively increased physical and mental wellbeing [1]. Thus, rehabilitation programs involving sports and physical activity can support a path back to everyday life for all family members. Additionally, sports can positively influence the psychological wellbeing and quality of life and the results of rehabilitation [2, 3]. However, for most of those studies' adult patients were examined and rarely children. Also, the interventions were mostly for a period of many weeks within a rehabilitation center with a focus on primarily physical effects [4].

Huang & Ness summarized 15 physical intervention studies with children suffering acute lymphatic leukemia (ALL) that

were conducted and published from 1993 until 2011 [4]. The sample sizes were generally low and the interventions comprised several weeks. The investigated parameters were immunological functioning, cardiovascular fitness, power, flexibility, the fatigue syndrome and quality of life. For the latter six of the studies showed positive effects that partly remained sustainable for more than one year.

Dimeo et al. also describe a strong link of body, psyche and social environment [5]. Negative emotions of children or other family members such as anxiety, hopelessness and uncertainty can lead to physical issues and detriments of functioning and capacity. This has in turn a negative influence on the psyche. The loss of physical and mental capacity can lead to an increased immobility which can have negative effects on the recovery process which in turn can lead to another stationary stay in hospital and thus again a prohibition of movement and a lack of motivation to be physically active. This usually triggers immobility and the patients have seemingly no chance to get rid of this vicious circle (see Figure 1) [6]. It comes to a so-called chronification of the problem. Hence it is important that the children are in a comfortable environment during the cancer therapy and rehabilitation.



**Figure 1:** Chronification of the Vicious Circle

It is evidence-based that physical activity has positive effects on the psyche and the mood of people. Training on a regular base can lead to an improved memory function, concentration and alertness [5]. Due to these positive effects physical activity is usually also recommended within the treatments of psychological issues such as depression or anxiety disorders. Sports can be helpful for patients while having the disease, but also for other family members to reduce stress and other concerns. Just after a few minutes of physical exercising the concentration of the neurotransmitters dopamine and serotonin are measurable in the central nervous system. Serotonin for example acts modulating on several brain functions such as perception and sensation as well as the mood and awareness of humans [7]. According to Trepel dopaminergic neurons have intense projections in the limbic system and play an important role for the influence of psychological processes [8]. The release of these two neurotransmitters can bring out a feeling of relaxation and aid the reduction of mental stress.

Sports can also contribute to a positive development of the self-image and an improvement of the self-esteem and the general condition. Another benefit can be the social interaction of sports in a group as contacts and options for social exchange can emerge for the affected. Further the participants encounter each other on a physical level and can talk about experiences while they have to master a task together [5].

Patients often experience physical symptoms such as impaired capacity or even amputated limbs which can mean a stressful stigmatization for the patients which often leads to social issues such as isolation. Concurrently (or partly as a result of this) psychological stress arises such as anxiety, exhaustion, helplessness, despair and depression. Many of the cancer patients have to cope with such negative effects after the initial diagnosis and also during the therapy and follow-up care psychological, physical and social stress are steadily prevailing. The symptoms can occur at distinct times and to different extents. They all hamper the return and reintegration of the patients to a 'normal' daily life though [6].

Generally, the meaning of the terms 'quality of life' or 'psychological wellbeing' or 'psychological functionality' differs from that of a healthy person to that of a sick person and particular aspects should be considered individually [2]. For that matter a sub-study of a more comprehensive investigation was conducted on a family-oriented winter sports rehabilitation week (Winter Camp) with the aim to find out whether this Winter Camp has an influence on the pillars of health (physis, psyche and social living according to the WHO) and specifically the childrens' psychological wellbeing after the journey. The study was conducted by the Department of Sport Science of the University of Hildesheim in cooperation with the Department of Psychosomatics and Psychotherapy of Medical School Hanover.

After several months of therapy with partly hard physical and mental stress for both the children and their families, the Winter Camp (including a preparatory seminar for involved students named "Wintersports in the rehabilitation of pediatric cancer Survivors") enables the participants to travel again without being entirely self-guided. The children test and regain their capacity and should subsequently easier be reintegrated to physical education in school. About ten families and up to 50 persons in total participate including about ten students that instruct all participants in skiing. This team also organizes several activities during the afternoons and evenings such as playing games, hiking at night, campfires, little performances and collective cooking. The concept is generally based on the three pillars of health and contains a specific teaching method that facilitates motor learning for patients [9-12]. The days with skiing as the main activity were planned beforehand and individually adjusted in daily team meetings in order to reach an appropriate activity level and learning success, but concurrently not to overcharge anyone according to individual requirements and capacities. We had clinic staff available for psycho-social support as well as for medical treatment if needed. Many other aspects as part of the comprehensive concept that serve the best possible rehabilitation effects can be read in Kurpiers [13].

### Methods and Material

The study took place on the Winter Camp in Austria. The questionnaire has been filled out by twelve parents online (45.17 yrs.  $\pm$  7.87 yrs.). The diseased children involved five males and three females (10.87 yrs.  $\pm$  5.33 yrs.) all of which suffered acute lymphatic leukemia (ALL) previously and their acute therapy was between five and 12 months ago. The parents signed informed consent, a protection of privacy policy and a declaration for voluntary participation prior to the journey.

All parents filled out the questionnaire once before (pre-) and once after the Winter Camp (post-survey). The pre-survey was conducted at the first and the post-survey on the last evening of the Winter Camp.

The results were gathered via an online survey-tool. The resulting values were subsequently analyzed using the statistics program SPSS (Version SPSS Statistics 26 for Windows). Afterwards the significance was checked using a U-Test. With this test the significant difference between the distribution was tested using ranks instead of parameters of distribution [14]. The significance was defined at  $p=0.05$ .

The survey instrument was the German version of the Strength and Difficulties Questionnaire (SDQ) (Klasen et al., 2003). It disposes 25 main-items that are distinguished into five scales respectively. These scales comprise the social behavior, hyperactivity, emotional problems, problems with peers and behavioral problems [15]. The possible overall score was 40 and Cronbachs alpha in the current sample was  $\alpha=.81$ . In addition, parents were asked how their child had benefited from the Winter Camp.

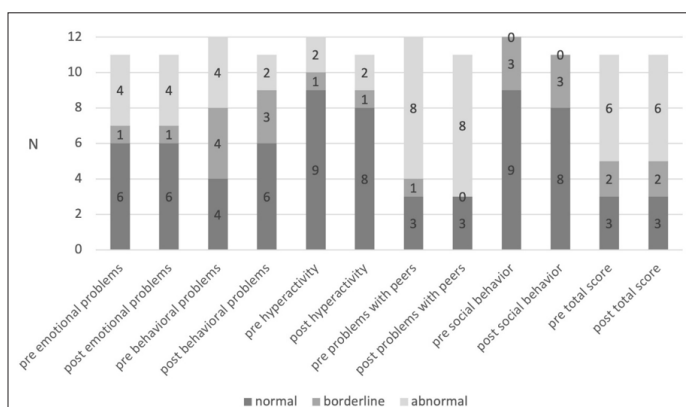
### Results

There were no significant differences between pre and post for the total score and the subscales of the SDQ (see Table 1) with the exception of the subscale behavioral problems where the mothers rated the behavioral problems of their children significantly lower after the Camp than before ( $z = 2.33$ ,  $N - \text{Ties} = 6$ ,  $p = .020$ ).

**Table 1: Pre and post differences between the total score and the subscales of the SDQ (N = 9 mothers). SDQ = Strengths and Difficulties Questionnaire; M = mean; SD = standard deviation; IQR = Interquartile range. \* p <.05**

SDQ	Mean (SD)		Median (IQR)		z	p
	pre	post	pre	post		
Emotional problems	4.56 (4.25)	4.89 (3.95)	3 (9)	4 (8.5)	.736	.461
Behavioral problems	3.44 (1.13)	2.67 (1.0)	3 (2)	3 (1.5)	2.33	.020*
Hyperactivity	4.22 (1.92)	4.56 (2.07)	3 (2.5)	4 (2.5)	.750	.453
Problems with peers	4.56 (1.59)	4.56 (1.74)	5 (3)	5 (3)	.000	1.00
Social behavior	6.56 (1.67)	6.89 (1.69)	6 (2.5)	7 (3)	.750	.453
Total Score	16.78 (6.32)	16.67 (5.96)	18 (10)	18 (9.5)	.000	1.00

Most children were rated by their parents in a normal range on the scales of the SDQ (see Figure 2).



**Figure 2:** Classification of the pre and post indications on the SDQ (N = 12)

Comparing the values of the sub-scale “emotional problems” to the raw value intervals, they have a total mean of all participants of  $4.27 \pm 3.8$  prior to the Winter Camp and  $4.36 \pm 3.7$  afterwards. Both values need to be categorized ‘borderline’ and only change marginally through the journey.

The SDQ-scale „Behavioral Problems“ shows generally lower values. Here the comparison of pre- and post-survey shows a significant positive change ( $p=0.035$ ; U-Test) in terms of rage, disputes, lies and the general obedience.

Within the sub-scale „Hyperactivity“ two participants are categorized ‘striking’, one is ‘borderline’ and all others are ‘unremarkable’ in both surveys ( $p=0.35$ ; U-Test). This category, however, is hard to interpretate as a lot of action is offered on the Winter Camp.

For the sub-scale ‚Social Behavior‘ high mean values are obvious. For five of the participants the values of this category increase during the Winter Camp.

For the sub-scale ‘Problem with Peers’ the pre-post-differences are non-significant ( $p=0.1$ ; U-Test). Infoboxes 1 and 2 show selected examples of answers of the parents for the open questions whether

and how their children did benefit from the journey and whether their expectations were confirmed. These answers were explicitly positive.

**Infobox 1:** Selected answers of parents to the question: “Wherefrom could your child particularly benefit

Even if she feels bad, she can dare to take an action, do sports.
That the pure joy of life is the most important at this Winter Camp, that he could learn at his individual pace, that he gets a feedback of his own strengths from people other than family members (and beyond the evaluation system at school).
Independence gets supported and to push boundaries and to think about and deal with own shortcomings; and our temporary separation from each other is good for the both of us.
The self-confidence improved remarkably; physically more capable; initial anxiety is overcome. The child has a lot of fun. Positive experience within a group. Sports at fresh air. Children are motivated by fun to be more active and do more.
Not to be/feel focused on all the time, but being directed by the group
Skiing, skiing, skiing. Perfect guiding and care by the students and a lot of fun for the battered soul.

**Infobox 2:** Selected answers of parents to the question: “Were your hope and expectations regarding this Winter Camp confirmed? If so, in what way?”

All expectations were exceeded. Extreme progress within a short time period compared to a ‘classic’ rehabilitation.
In any case: Sports, Community, mountains, support. All perfect.
Being together, talk with each other.
I have reconquered a piece of life quality; Pitztal is the best week in the year – let go and still be me myself.
Yes, one week completely off everything– and regain energy.
Yes, my child’s anxiety fade into the background
Yes, positive experiences from the previous year were confirmed
Yes, relaxation and fun!

## Discussion

In this study a specific rehabilitation winter sport week for the families of childhood cancer survivors was evaluated regarding their psychological wellbeing using a validated questionnaire. It was a sub-study of a more comprehensive investigation conducted by a Medical School and involved open and closed answer options. Besides the guided sports activity skiing several other activities and impressions have to be considered to have a notable influence on the participants’ mood and wellbeing. Thus, not skiing as such can be interpreted as an effective sports discipline but the Winter Camp and its general concept.

It is apparent that only the sub-scale ‘Behavioral Problems’ ( $p=0.035$ ) changes significantly from the pre- to the post-survey when summarizing the sub-scales in the sum scores. Thus, regarding the closed answer options of the survey no significant effects of the Winter Camp could be assessed for the psychological wellbeing or the children in such a short time period. However, giving a deeper look on the evaluation and the open answer options, a different impression emerges. The participants wrote that the Winter Camp had a strong positive effect on the psyche and the wellbeing for the whole families. All parents indicated that their children were very or extremely satisfied with the rehabilitation program and that the journey helped them to perceive their strengths and weaknesses. The physical capacity of all children has also improved according to the parents. In terms of psyche and life quality the Winter Camp had primarily positive effects on the

social togetherness of the children, the psychological wellbeing of both the children and the parents as well as the atmosphere within the families. According to the open answers regarding the best benefits for the children (Infobox 1) independence and self-confidence were the outstanding aspects that were mentioned by the parents. This is underlining a successful development due to the well dosed mixture of guidance and independence beyond any interventions through the family members that are present and reachable, but not in charge and temporarily not responsible. Another parent emphasized the improved physical fitness, positive experiences within the group and the resulting motivation to keep going which apparently affects their life quality. This matches with the results of Speyer et al., who found an increased health-related life quality after several repetitions of three days sports interventions in addition to the conventional therapy compared to the control group consisting of treated children without the sports intervention [16].

One family answered the question why some families joined the Winter Camp for the second time and if they would like to join it again that this is due to the possibility to concern themselves beyond everyday life with physical and social aspects of life and to grow with that and because the pure joy of life is hardly better tangible than on this journey. One mother stated that she knows that her child feels definitely strengthened and that she smiles more often than before. Another mother said that the Winter Camp is good for their family as they find a way to come back together and talk to each other. It is also a particular highlight for the healthy sibling which opens up much more and becomes happier again. There is the so-called 'Winter Camp-mode' (as a common term for several families) which means happy, well taken care of, (almost) worry-free, at capacity. These statements illustrate the positive effects of this week on the whole family as well as the increase of psychological wellbeing. These personal statements as open answers show that there is a lot of positive development and changes regarding physical and mental activation which is apparently in turn not well demonstrable via the SDQ-questionnaire with closed questions. That may be due to the fact that other aspects get surveyed in the closed questions that are relevant for the subjectively perceived psychological wellbeing on the one hand, however, specific aspects as stated by the families in the open answer mode are not captured. The open answer options show a very clear improvement of the mood, the atmosphere (individually, within the group and within the families) and thereby the life quality. Another reason for this assessment-difficulty may be the short intervention period. A longer intervention could possibly consolidate the impressions and perceptions and thus lead to other checking behavior with the checkboxes.

Also, the personal conversations with parents gave an exclusively positive feedback about the Winter Camp and its effects on the families. One mother reported that after the diagnosis and especially due to a relapse her daughter developed a deep sadness followed by a huge anxiety to die so that she isolated herself from her social environment. The psychological symptoms were followed by physical issues such as headaches, abdominal pain and dizziness. Due to the Winter Camp and according to the mother her daughter felt glad and free again and she perceived her daughter as self-confident with an improved body image. This and other statements are supported by the exemplary comments in Infobox 2.

Our study from 2018 also showed that a comparably short intervention period can still lead to positive effects. A significant increase in balance ability has been measured after one week of skiing in pediatric cancer survivors [17]. Däggelmann and

colleagues also showed an improvement of motoric parameters after a sports intervention with an adventurous character, however, the intervention period was ten weeks. The positive effects of a movement therapy of Mueller et al. on the health-related life quality has also been assessed after four weeks for immediate as well as after twelve weeks follow up for sustainable effects [18, 19]. Another research group conducted an intervention review and found generally positive intervention effects for body composition, flexibility, cardiorespiratory fitness, muscle strength, and health-related quality of life (cancer-related items) [20]. However, it was concluded that the effects of physical activity and exercise training for childhood cancer participants are not convincing yet, presumably due to small numbers and insufficient study designs.

The present literature base underlines the tendency of the current study that physical activity can improve psychological wellbeing on the one hand. On the other hand, the current ski intervention was comparably short with only one week and the qualitative results (comments) were much clearer than the quantitative results from the closed questions survey.

When this study was conducted it was obvious that the sample size of twelve participants was quite small and the intervention period with one week quite short. Both aspects, however, were a matter of feasibility. Moreover, some technical difficulties emerged while answering the questionnaire online (e.g. connectivity, no function to browse back etc.) why either the feasibility and the online tool needs to be optimized or a conventional hard copy mode needs to be considered for similar future studies in order to be more independent and timewise more flexible (e.g. regarding breaks).

A limitation of the SDQ-questionnaire is that no age- or gender-specific differentiation exist. However, males are generally rather more hyperactive than females who in turn show more often a social behavior. The time elapsed since the initial diagnosis might also be a relevant factor. Shortly after the initial diagnosis the children and their parents are usually in a state of emergency which can reflect in the childrens' behavior and psychological condition.

Within the framework of this survey it became obvious that a family-oriented Winter Camp may have positive effects on the psychological wellbeing for pediatric cancer survivors and their families, however, a qualitative approach (open comment opportunities and interviews) was more feasible and relevant for this one-week intervention than the quantitative approach with closed answers.

The evaluation of the Winter Camp was consistently positive or even enthusiastic and the parents assessed the value of the journey highly beneficial for their children. Such a week means an escape from everyday life which is mostly rather negatively connotated at such hard times. They can temporarily neglect negative or careful thoughts related to the disease and the therapies, exchange experiences and mindsets and just have a good time in the mountains. Additionally, they all benefit from the sport: cenesthesia, body image and perception get trained and improved, the children get their self-confidence back and experience capacity limits. Also, their social skills get applied and thus trained and they are not primarily focused which is particularly beneficial for the healthy siblings. We investigated short term effects here, but we have pointers that those effects stated in the free answer options last for longer. In a different study in the same context the parents also reported in interviews subsequently that the whole families still lived on this Winter Camp for many months with a distinct gain in life quality [21].

The topic, sibling-children' is a topic on its own and should be more focused on in such a context in the sense of specific studies. Such studies are currently under preparation.

In conclusion, purposeful rehabilitation journeys with an outdoor sport emphasize can be beneficial for the recovery of pediatric cancer survivors with respect to their wellbeing. Within that framework it was found constructive to offer the right setting and respective offers and options in terms of communication, meetings and also opportunities to retreat, movement experiences, instructions, flexibility regarding group arrangements, load intensities, breaks, general care and support key. The rehabilitation journey, multiple times positively evaluated regarding motor parameters and physical effects, could now at least be recommended on a psychological level according to the participants.

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