# Germany's First Young Carers Project's Impact on the Children: Relieving the Entire Family. A Qualitative Evaluation

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**Abstract:** *Background*: In 2009, the first German young carers project "SupaKids" was implemented in a large German city. The project's concept was mainly based on findings of a prior Grounded Theory study, and the concept's aim was to focus on supporting enrolled families (especially the children) in order to prevent negative effects. Quantitative as well as qualitative data have been assessed for the project's evaluation. In this paper, first results on the mainly qualitative evaluation concerning the project's impact are presented.

*Results*: The project has an impact on the entire family. Both parents and children perceive the project as a kind of shelter, where they a) are allowed to be as they are, b) don't have to explain themselves, c) meet others in similar situations, d) may deposit their sorrows, e) have a first port of call for any problem, f) experience a hiatus from the domestic situation, and g) find friends and peers. All enrolled families value this shelter as a copious relief.

*Conclusions*: The project's concept has delivered an optimal performance in practice: the family-orientation seems to be appropriate, the concept's modules seem to be all-embracing, and the modular body of the concept has been confirmed. The project relieves the entire family.

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**Keywords:** Young-carers, evaluation, complex intervention.

## BACKGROUND

Young people below the age of 18, whose lives are affected by looking after a relative with a disability or long-term illness, are called *young carers* [1, 2]. In 2009, the first German young carers project "SupaKids" was implemented in a large German city [3, 4]. The project's concept was based on findings of a Grounded Theory Study [5, 6] (which was carried out by one of the co-authors), and its effectiveness was planned to be measured in an RCT using health-related quality of life (HRQOL) as the outcome criterion [7, 8]. The scientific part of the study was funded by the German Federal Ministry of Education and Research (BMBF, Funding Reference Number 01GT0619) while the practical implementation and realization is funded by the host organization and one of Germany's biggest foundations [4].

Findings from the prior Grounded Theory Study [5, 6] identified that young carers may suffer from their situation in the following ways:

- having no one to talk to
- living in secrecy
- lack of free-time
- social isolation
- problems in school and missing time in school

- strong parental attachment
- feelings of loneliness, shame and fear
- physical and mental exhaustion

Thus, the project's aim was to focus on supporting families (especially the children) in the above mentioned fields in order to prevent negative effects on the children's overall development. However, a central concern of the concept is its family orientation. Different families share common needs, but, in their everyday life, individual families, as well as individual family members, have their individual problems, needs and demands, and these require individual support [5]. To face commonalities as well as differences, support consists of different modules (Table **1**), which can be flexibly offered according to a family's specific situation. Thus, the intervention may differ from person to person.

The project takes place in an independent youth center, where the children meet for some hours twice a week (so called "young-carers-group"). During holidays, a daily leisure-time program is offered. For the parents, there are general breakfast-meetings every other week. Additionally, there are festivities for all families each quarter (a detailed description of the project's content is described elsewhere [3]). Access to the project has no time limit, and participating families are free to stay within the project as long as they wish. Although one characteristic of the project is its family-orientation, the main focus on evaluating the project's effectiveness is set to check its impact on the children.

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**Table 1.    Intervention Modules**

| A) Having Someone to Talk to | B) Support for Children | C) Support for Parents |
| --- | --- | --- |
| Counseling for children | Leisure-time activities (young carers group) | Parents' breakfast |
| Counseling for parents | Information and education about illness and care | Administrative support and counseling |
| Family conferences | First-aid course | Flexible help with everyday life activities |
| | Schoolwork assistance | Family festivities |

The study faced several problems concerning the conduct and implementation of the project as well as recruitment for the study [4]. This resulted in re-structuring the scientific design from RCT to qualitative analysis in order to evaluate the project's effectiveness [4]. In what follows, first results on the qualitative evaluation will be presented.

## METHODS

### Aim

The aim of the study was to describe the families' experiences with the project and to evaluate the intervention's impact on the children.

### Data Collection

Data was mainly gathered using

1.    problem-oriented interviews [9] with a) children ($n = 5$), b) parents ($n = 4$) and c) project staff ($n = 4$), focusing on their experiences with the project.

2.    extensive case-files of every family, as recorded by the project's staff (social workers, family-health-nurse)

3.    participatory observation during the young carers groups, focusing on how the children behave in the group.

### Data Analysis

Interviews were audiotaped and transcribed verbatim. Each interview was read and listened to several times to get an overall impression of the experiences, and preliminary findings were discussed among the authors. Following the framework approach to qualitative analysis [10] interviews were coded according to themes and sub-themes, and the codes and their definitions were refined collaboratively during the process. Data from participatory observation as well as from the case-files were used to confirm, modify or to discard codes. As the analyzation went on, axial coding [11] became more and more important in order to specify the relationship between themes.

### Ethical Considerations

The study's proposal was sent to the Ethics Committee, Institute of Nursing Science, Witten/Herdecke University (EKIP) which had no objections to the study. Participants received written and oral information about the study, and prior to each interview participants were explained the purpose of the assessment. Informed consent was requested from both parents and children. It was repeatedly stressed that participants had the right and opportunity to withdraw their consent at any time.

### Participants

In sum, 27 families called the project and asked for information about the offered service. 10 families finally enrolled into the project. After three months, 3 families dropped out due to personal matter, as the health-status of the ill family member improved significantly. In sum, 5 children and 4 parents gave consent to be interviewed. Table **2** gives an overview of the 6 enrolled kids who visited the young carer group for half a year. All of these children cared for their mothers, who all are suffering from a somatically illness. Half of the children are living in single-parent-households. Their expectations from the project are mainly *leisure-time activities* and *befriending*, while their parents' expectation is predominantly *companionship*.

In what follows, four of these children will be presented as exemplars in order to demonstrate the complexity of the cases.

### *Trixi*

Trixi was the first child that enrolled into the project. She was 12 years old when she joined the project in March 2010. She lives with her mother, who suffers from Multiple Sclerosis (MS). Her mother made the initial contact with the project in order to get support for herself and her daughter. The mother describes the parent-child-relationship as declining, with Trixi being a pubescent teenager having problems in school. Additionally, Trixi's mother feels herself too weak to set boundaries and to sustain parenting. Trixi experiences this weakness as a lack of interest. The overall domestic communication between the two is low.

While Trixi had no expectations from the project, her mother hoped that Trixi would benefit from meeting other young carers and from the leisure-time activities. For herself, she asked for support concerning housework and shopping. Trixi visits the young carers group while her mother joins the parents breakfast.

### *Pia*

Pia was seven years old when she enrolled into the project in May 2010. She lives with her parents and an elder sister, while her elder brother already moved out. Her mother suffers from an ovarian carcinoma and gets chemo-therapy for the last time. The prognosis is bad, and after this therapy she has exhausted all treatment options. Pia is obese and has no friends in school. She is bullied by her classmates and she shows affective behavior as well as aggression. Pursuant to her mother, she is socially isolated. Her mother mainly called the project to get social support for Pia. Pia knows

**Table 2.    Profiles of Children**

| Name | Trixi | Hannes | Pia | Michael | Ben | Malte |
|---|---|---|---|---|---|---|
| Sex | female | male | female | male | male | male |
| Age | 13 | 13 | 8 | 11 | 8 | 11 |
| Enrolled | March 2010 | May 2010 | May 2010 | June 2010 | June 2010 | October 2010 |
| Parents | single mother | single mother | mother and father | mother and father | mother and father | mother and father |
| Siblings | no siblings | one younger sister | one elder sister, one elder brother (moved out) | brother (Ben) | brother (Michael) | no siblings |
| Ill person | Mother | Mother | Mother | Mother | Mother | Mother |
| Illness | Multiple sclerosis | Rheumatism, Epilepsy | Cancer | Multiple sclerosis, Arthritis | Multiple sclerosis, Arthritis | Ulcerative colitis |
| Project info through | Internet | child psychologist | psychotherapeutic day hospital | charitable trust | charitable trust | Newspaper |
| Dominant problems (as seen by parents) | social isolation, decreasing school performance | affective behavior, aggression | social isolation, being bullied, affective behavior | decreasing school performance | being bullied | social isolation |
| parent's expectations from the project | companionship, administrative support | companionship, leisure-time activities | companionship, administrative support, emotional support, befriending | companionship, leisure-time activities, befriending | companionship, leisure-time activities, befriending | companionship, befriending |
| Children's expectations from the project | leisure-time activities, befriending | leisure-time activities | leisure-time activities, befriending | leisure-time activities, befriending | leisure-time activities, befriending | leisure-time activities, befriending |

about the fatal course of her mother's illness and she suffers from the thought of being left alone. She mainly stays at home watching TV. She is very afraid that her mother could collapse while she is at home alone with her mother, and Pia does not know how - or even being unable - to act. During the hospital phases of her mother, she visits a psychotherapeutic day hospital in the same clinic as her mother.

Pia's expectations from the project are mainly befriending and leisure-time activities, while her parents hope to additionally get emotional support and companionship for her. Both parents don't visit the parent breakfast, as Pia's father works, and her mother feels afraid and unable to leave the house on her own.

***Michael and Ben***

Michael was 11 years old and Ben was eight when they joined the project in June 2010. They live with their parents, and their mother suffers from various diseases, mainly MS and arthritis. They live next door to their grandparents, who have a problematic relationship with their mother. Their father mainly works in night shifts, with their mother takes care of them during the day.

Michael is caring for his mother since he was four years old. As his mother suffers from a MS induced amblyopia, he used to be her eyes, as the mother described it in her interview. Michael is very cautious in terms of his mother and brother, and he feels responsible for their safety.

Ben's hearing was impaired from birth, but his hearing increased after several surgeries. However, his linguistic

development is not age-appropriate. He visits a school for children with speech and language handicaps.

Both Michael and Ben help with cooking, housekeeping and doing the laundry.

Their mother called the project in order to offer her children time-off from the situation at home.

Additionally, she needs support in explaining her illness, its aetiopathology as well as the symptoms to them. For herself, she asks for administrative support and companionship.

Michael and Ben visit the young carers group while their mother joins the parent-breakfast. Michael additionally gets tutoring in the school subject *English* by a project's staff member.

**Findings**

The experiences made by the participants are partly comparable, but children and parents have different key aspects. However, before experiences can be made, there is the participants' way *to* the project, which is remarkably long.

**The Way to SupaKids**

In all participating families, it was the ill parent who got the first information about the SupaKids project. They obtained a flyer about the project when they were at the doctor's, at the hospital or from other aid projects. Direct first contact with the children did not take place.

As soon as the parents have the flyer to hand, a decision-making process is provoked whether to call the project or not. At this juncture, it is essential that the parents first of all acknowledge that they cannot cope alone and require assistance. The parents describe how their decision to contact the project had to first mature in their minds. To accept help is difficult, and its acceptance is perceived as an inner barrier. This process can take months. A mother said:

> "Perhaps it takes a bit until you have the guts to admit that you really need help. I can only speak for myself of how it was for me, and I think it's perhaps the same for others. They must first think, look, umm, is it possible, can I do it?"

The parents balance various motives why to call the project. For all of these, the children's needs stand at the foreground. Firstly, they realize that they do not function like other parents, and that they cannot amuse their children as they would like to. They wish to enable their children for leisure-time activities and social contacts. On one hand, the illness does not allow for shared activities. On the other hand, they don't have the energy to stand noisy children all the time. Thus, they seek a place where the needs of the children are spotlighted, where the children can let off steam without having to consider others. A mother said:

> "That Mom's no longer like she'd like to be, and sometimes puts her feet up according to the motto, shut your trap, don't say another word. And here [at SupaKids] that's natural, where they can really be what they are. Simply be children."

Furthermore, the parents are aware that the children are burdened due to the illness and need a break from home. They wish for a place, where their children can forget their worries, where they are taken away from their everyday life and experience a time of carefreeness. The information about SupaKids raises the hope that they might have found appropriate support. This hope triggers the willingness to even reorganize the family's weekly routine in order to allow the children to take part as often as possible. If it is the appropriate time, a small incident in daily life, for instance the symptomatic deterioration, triggers the actual establishment of contact.

> "Yes, because at that time I really had problems, also with my daughter, and then I somehow thought it's all too much for me. I'll give them a ring, and have a look at what it's about."

The parents first make the contact and then inform their children about the project. The children also have their doubts at first, about whether they should accept the offers available or not. A young carer described it as following:

> "So, I must actually say, well beforehand I didn't want it at all, because I thought that's just, that yeah that they only handled me somehow somehow differently or so no idea"

And a boy added:

> "I've considered, whether one can go there"

Once they take part, the children like the group from the very beginning.

## Being at SupaKids

Concerning the experiences with the project, children and parents share similar phenomena. However, different key aspects are of importance for the two, which will be described in the following.

### Children: Being a Child without Requests

Concerning the children's experiences, the phenomena *"Being a child without requests"* is the key aspect for the children. They are aware that SupaKids is an offer for children, whose parents are chronically ill, and that they (the children) may take part in the group on the grounds of the illness. They come willingly into the group, and the offer has a great significance. They appreciate the casual play facilities, as well as the contact between equally affected children. The children are taken out of their everyday life and experience a time of carefreeness, in that dropping everything drops from them, and they can at last *"really"* play. Different from school, where they more likely have the status of an outsider or "nerd", where they have hardly any friends and are rather bullied, at SupaKids they are equally integrated into the group. A young carer answered the question what she likes most at SupaKids with the words:

> "That I found friends here"

At SupaKids everyone can be just the way he or she is. A mother describes it with:

> " and that's why they gladly come here, here no one discriminates them, no one says to her you fat cow, and insults her or hits and kicks her. They savor that very much, because here all are so different and each one is allowed to be different. Unfortunately, this is not conveyed to the children in the schools of today."

For the children it's important that they have peers. The group is very heterogeneous regarding age, gender, and social background. Nevertheless, they harmonize strikingly well. In the group, the children care for one another. The group cohesion is good, there's a strong connection. In the group the children experience for the first time, that they're not the only ones whose household situation is dominated by illness. They see that others live in similar situations at home. They all have their eggs in one basket, they know "it's also similar with me", and that bonds them. This is evident above all in children who are new to the group. They don't have to actively integrate themselves into the group, they automatically belong to it. The peers at SupaKids define themselves not by age, gender or hobbies, but the illness. One staff member formulated it like this:

> "I believe that they all know about the others, that they don't have it easy at home. And I also think all have experienced the situation, of how it is to be alone and have a lot of responsibility, and that's why they can put themselves in the others shoes. Yes, and when someone new, for example, comes into the group they are immediately integrated. And I

believe they can identify themselves with the others, because of the circumstances at home. They have a lot of empathy."

Furthermore, *being a child* does not only mean to have friends, but *to do* things together. Thus, not only the young carers group, but also the additional activities have a great significance. Thereby, it's not so much *what* they do, but rather *that* they do it together as a group. Older children for example, enjoy to take part in excursions and projects, that are rather more focused on younger children. Thereby the activities offered must not be extravagant, as the families are rather modest. Besides financially demanding excursions, such as a visit to the zoo or circus, simple activities such as a visit to a park, are gratefully accepted and appreciated. A mother describes it with:

> "Above all it's that this offer even exists. It doesn't have to always be Hagenbeck zoo or Roncalli circus. Simply get out into the countryside. That costs no money, costs only a ticket, that costs no money. Just go and collect leaves or chestnuts. That's nice."

In their eyes, SupaKids cando many good things that are not a matter of course.

Besides *being a child* the addition *without requests* is important. For some children, SupaKids is the first opportunity to get away from their responsibilities at home. They are taken away from their everyday life and experience a time of carefreeness, in that dropping everything and they can at last "*really*" play and let off steam. To allow for that, they follow the strategy of *keeping the illness outside, but leave the door ajar*. Illness is hardly ever spoken about within the group. Thus the corresponding concept modules (cf. Table **1**), which intend that the course of the illness, the symptoms and treatment strategies, as well as first-aid techniques are conveyed in a child's appropriate language, are only indirectly addressed. The children want to learn about this, but from their point of view it should be so, that the staff gives indirect proposals, however, such conversations should not be forced. A child paraphrased:

> "Perhaps not everyone likes that, that everyone latches on that wouldn't be so good "

This information should, from the children's perspective, be imparted by books, leaflets or comics. They like to study it alone and quietly for themselves. A young carer described it so:

> "Okay, I think with older children, they already know everything. But the little ones there you could definitely do it, but then with... with something like comics or so and then during the period not to thematize it."

Another girl responded to the question, what the team of a fictive new SupaKids group definitely should not do, with:

> "Not to speak about the illness!"

The children, even among themselves seldom exchange confidences with regard to the illnesses. When this happens then it's usually incidental, for example in subordinate clauses.

> "Yeah, we already know thereabout [what illness the parents have] because during festivities or such, then you see the parents. But we don't talk about it now. We really have other topics."

The team members confirm the views of the children. They are very carefully awaiting â€œthe right momentâ€, to speak quietly and alone to the staff about illness-related problems. This takes place mainly at the end of the group meeting, when the others have already gone. However, even then it's mainly to pick up leaflets, magazines or books, so that they may at a later date clarify open questions.

Being at SupaKids has an impact on the children. All parents describe changes they have noticed in their children, which can be traced back to the project. In their eyes, particularly the frustration level has decreased significantly. The children can better channel their wants and energy, because they know that at SupaKids they are free. Then, it's easier for them to show consideration at home.

> "They're more even-tempered. When I now say, listen, at the moment I can't do it because of my health, they accept that now. Yes, that's changed. They try to be much quieter. But there [at SupaKids], there they can romp and play football."

The parents describe how their children have become more open. The project is a place, where the children can be themselves. From this the children reach a kind of "I'm Okay"-attitude, which allows them to be more self-confident and open.

> "She realized, here everyone starts from scratch. At school she really had a difficult time, she couldn't find any contact in the class. And since she comes here it's more relaxed. Now, we often speak with the teacher, and she also thinks that it has gottn a lot better."

And the father added:

> "In my eyes she has become more self-confident, and doesn't withdraw into her shell so quickly, I'd say she now doesn't avoid problems. And she gets on really great with the others, and when I see how they play in the group. She's not really a group person, and when I see here how she manages to structure herself, I'm really happy about it. Well, with this comradeship, she couldn't do it before"

The children themselves can't describe certain changes directly. For them the group is important, because they've found friends and received attention there.

### Parents: Finding Support

Concerning the parents, the phenomena "*Finding Support*" is a key aspect, which consists of "*Knowing the children at a good place*" and "*Experiencing encouragement*".

The parents are aware, that there are many things concerning leisure activities, that they cannot give to their children as they wish to. The group functions as a sort of

substitute for the parents. In that they send their children to the group, they take care of them. The group compensates for the gaps in regard to leisure activities and the imparting of skills. A mother describes it with:

> "That does me good! Because I simply can't do it, play the whole afternoon or do such exciting things as cycling. That I simply can't do. And the very thought, that I don't have to brood over â€˜what can you offer her today'. It's good that she's in good hands here for two days; she can play and romp as she wants and is also dog-tired, evenings just has a sandwich and quickly goes to bed. That also does me good, when I get peace and quiet early in the evening and I'm there only for myself".

Additionally, SupaKids supports the parents with educational responsibilities. On grounds of the illness, parents cannot maintain many social rules at home. They experience it as a relief that SupaKids sets clear rules, and see that they are upheld.

> "I'm often in hospital and can't set the pattern, and I'm dependent on the pattern set by my husband also, when I sometimes don't find it so good. Things where I would strictly say no are with him, yes and no. And that's good for them, that it's predefined. And I think it's also very important for the children, whose parent is often away or can't perform well. That's what the children need, and it's very important! When we say no, then it means no."

The parents find their attitudes and values being represented and lived at the project. By this, they know their children at a good place and they strive to make participation possible by all means. In the parent's eyes, talking about the illness during the children's group is a support in parenting. However, they see this topic if anything ambivalent. On the one hand they want that the project informs about illnesses. One mother said:

> "In principle, I would welcome something like that, whether Mom has MS or cancer is in this case totally irrelevant. Important is that the child learns how to deal with it, also that the child is taught that 'when your mom's not well you don't have to feel bad about yourself'. Or how do I behave in an emergency situation. As a mother I wouldn't like to have to teach her that."

On the other hand, the parents see that "light heartedness" stands at the foreground of the children's group. The children should play and have fun. The severity of the illness should not be actively raised in the group.

> "Trixie is certainly happy, when she doesn't have to hear about MS. I was already ill when I had Trixie, and she doesn't know me in any other way. She knows everything anyway. I don't believe she has any desire for such a topic at Supakids."

The initial contact with the project is made in order to get support for the children. After a short time, the parents realize, that they benefit as well. They experience the parent-breakfast as a place where they feel understood. They experience encouragement as well as companionship, and they can exchange their experiences, something which isn't possible in their whole environment. They learn that all those present deal with problems through their illness. They don't need to explain themselves, because it's similar for the others. The group offers them a place where they can forget their worries and are given courage. In the group one can swop experiences, laugh and cry together. One mother says:

> "Sometimes it's important just to have someone to talk to who listens. Where you can say, today's a shit day, tomorrow it'll be better. Everyone has something to tell, sometimes you laugh over it, and sometimes a few tears are shed. That's what's good about it."

At this juncture it was positively emphasized, that the project looks after the children as well.

> "I find it good, that you can simply talk to the adults, and tell them what problems you have. Because they know us both, me and my daughter, and that's really good."

The parent's group enables comparison, as well as problem participation among themselves. The latter, however, is ambivalent: The parents can see which symptoms in the progression of the illness may occur. On one hand, this enables them to prepare themselves for whatever symptoms and courses of the illness they will possibly be confronted with. They find out, which follow-up problems are associated to it, and which solutions and compensation strategies other families follow. On the other hand, it takes the hope of recovery away, for example the belief that "with me it won't be that bad" from the affected person. The project has an impact on the parents. Besides the feeling of being relieved and the possibility to share experiences, it changes the atmosphere within the families in a positive way. One mother, who suffers from incurable cancer, related that her daughter brought home the liveliness of SupaKids.

> "She's learnt so much here, also handicraft techniques It now hangs at home a very decorative mobile, and yes it brightens up the house, they hang everywhere colored balls and home-made things, paintings."

And she added

> "Usually, when I'm here, she hides herself in her room and doesn't say a word, is totally withdrawn. Because here at home she must face her fears in the face, and that's why I find it so good that at SupaKids days she comes home totally happy, and talks and talks and talks and even talks in her sleep. I find that really great."

The mother is relieved, that her child can have fun, even though her life is so difficult. Another mother said, that at the moment she had, if anything, negative topics of conversation with her pubescent daughter. This is, however, different on SupaKids days, where she comes home and tells

her mother what she did at SupaKids and how she had fun. From the children's point of view, the parents can address their worries during the breakfast and come home more relaxed and even-tempered. One child said:

> "I think it's good because I think there the parents can swop experiences and so yes that's also somehow good for the kids the parents are then hmm not so tense"

### Family: Togetherness and First Contact for Everyday Problems

Besides the experiences of children and parents, SupaKids addresses the entire family. Finally, the key aspects "*First contact for everyday problems*" and "*Togetherness*" are described.

The project doesn't limit itself to only the official offers, but furthermore provides support in everyday life. This part of the project's concept is well put into action by the staff, and it is greatly appreciated by the families. One young carer said:

> "I was also very often somewhere with the staff members. They also deal with things privately, or when I have problems."

And her mother added:

> "Yes, they're really aware of what's going on. And they were at my house, and have also helped me there."

The project is the families' first contact for all everyday problems. Thus, a young girl whose MP3 player had been stolen at school directly went to the project's office after school to report the theft, have a good cry and plan the next steps. Another young boy, who had been teased intensely during the break, had left the school premises and came to the project office to have a good cry. Only then did he, together with a staff member, inform his parents. A mother, whose son had bad marks in English, turned to the project with the question, whether someone could practice vocabulary with her son.

> "I grew up at the time of the GDR [German Democratic Republic], I can still speak a bit of Russian, but today that doesn't help anybody. My husband grew up at a children's home; he didn't have English there either. So who should I ask? And it's naturally a real relief, when you can say 'can you help, 'cos I can't do it'. And also you don't have to be embarrassed when you can't do something. Yeah, that's what I mean; we all have our mistakes and weaknesses. (…) and Juli said, okay let me know, and I'll come directly to you when I come out of the university."

In addition to the activities for parents (breakfast) and children (group) SupaKids offers quarterly activities for the whole family. On these family days they may, for example barbecue or celebrate Halloween. The families very much appreciate these offers, because joint family activities have been almost completely given up, and practically don't take place. These family events strengthen the togetherness. A young carer described it like that:

> "When we have these festivities, we can see the others' parents celebrating Halloween or having barbecue together *this* is important, too!"

And a mother added:

> "Well, and I know the other mommies, that is always really nice barbecue and so on. I go there with lots of pleasure, even if I don't feel good Having a talk with the mommies, this is really important to me. Honestly, I don't want to miss that!"

## DISCUSSION

### Initial Contact

In every family, the ill parent made the initial contact with the project. Apparently, addressing the ill person seems to be the only way to establish a connection between the families and the project. In the first place, the children don't perceive themselves as "young carers", hence they would not see themselves addressed by a flyer or an ad. Secondly, there is a "*code of silence*"[5, 6] in these families, as they often associate intervention from the outside with the risk of being separated. Therefore, family members usually avoid to disclose their need of support in order to protect the ill person as well as the entire family (ibid.). Seemingly, it is the ill family member's part to assume responsibility for reaching outside support.

### Time for Consideration

At its start, the project faced huge problems to get in contact with families concerned [4]. Two aspects explain this phenomena. On one hand, the population of young carers is hidden, unknown and probably underestimated [2, 5, 12]. Reaching this hidden group in one study (Grounded Theory study [6]) does not necessarily mean that this will succeed again in another study or intervention (current study)[4]. On the other hand, even if a family gets information about the project, they need a considerable time to decide whether to call the project or not. This implicates, that any similar project or research targeting this group must add in extra time for field access and recruitment.

Additionally, this shows that the current German health care system is not aware of this specific population and their need of support. Otherwise, there would be a more intensive collaboration between the e.g. hospitals, physicians, helpdesks and SupaKids or similar projects, focusing on supporting a) the decision process as well as b) confidence-building.

### The Project's Concept

The project's concept seems to be appropriate:

- The concept was developed with the persuasion, that management of chronic illness is a process in which the entire family is involved. Thus, its main characteristic is the delivery of comprehensive support from one source to the entire family. The interviews show that the families value this approach.

- Until now, there has not been a single request concerning support which could not be covered by a project's module (cf. Table **1**).

- The modular body of the concept has been confirmed. Participants appreciate the possibility to call on specific modules without being *compelled* to do so.

The latter is remarkable, as - for example - the concept's authors put focus on the modul "Information and education about illness and care" (cf. Table **1**), which was supposed to be an important component for the groups. Each enrolled child stated clearly their unease to thematize illness in the group. They value the possibility of asking questions or obtaining leaflets at the time *they* wish to.

The project does have a core content, namely the informal group meetings for both parents and children. However, SupaKids' strength is the individual approach determined by the individual case, which might go beyond the official offers. Fosbinder [13] has already described this as "going the extra mile", which is beyond the expected support and friendly care. This individual support mainly contributes to the families' overall relief.

### Contrast to Other Leisure Facilities

There are plenty of alternative leisure facilities for children and adolescents available, e.g. scouts, sport clubs or youth projects. Fact is, that these children hardly attend them. In contrast to those, SupaKids' main characteristic is its unconventionality:

- Participants are free to take a part or to skip activities or meetings without having the need to call in or to explain themselves. As one characteristic of chronic illness is its unpredictability, participants appreciate the informal character of participation which leaves them the freedom to make decisions spontaneously. Additionally, due to a long school day, some kids are only able to come to the group because they are free to show up there even hours after its official beginning.

- There is no goal to reach and no competition to run. Most of the alternative leisure facilities focus on assertiveness or a specific objective to be accomplished. For example, sport clubs are more or less performance-oriented, and participating children are expected to perform at one's maximum level in order to be nominated for the team or to win a championship. This might be deterrent for young carers. Their everyday life is dominated by their *very personal competition* in managing the daily course of life. Additionally, if they miss a meeting or training module, they will have to catch up next time in order to not fall behind. At SupaKids, young carers appreciate the *hiatus* from competition and responsibility.

### The Project's Impact

The project does both the parents and the children good. The key issue for both is the peer aspect. They experience for the first time that their situation is not unique. By sharing similar experiences, they overcome the feeling that no one understands what it means to manage chronic illness in a family. This leads to an increase of self-esteem. For some children, SupaKids is the first opportunity to get away from their responsibilities at home in order to do what children usually do: meet friends, play and have fun together with others. They get away from their daily sorrows and experience a time of carefreeness. This influences their mood in a positive way and lets them re-energize. Thus, they are able to manage their hindered daily routine for the next days.

Each single intervention has an impact on the entire family:

- Although the young-carers-group deals with the children only, it causes an additional impact on the parents: they feel unburdened, they have time for themselves, they experience liveliness and regain positive conversation topics.

- The parents-breakfast deals with parents only, but this causes an additional impact on the children: they experience their parents to be unstressed, a condition which influences the atmosphere at home in a positive way.

This strengthens the understanding of family as an associated system: interventing at one gearwheel affects the entire system.

### Hard Data

The original study design intended to carry out an RCT in order to produce so called *hard data*. A power- and sample calculation advised to recruit at least 150 children [3]. With the experiences of the SupaKids project it is arguable whether it is realistic to sucessfully complete such a study. As for SupaKids, one can sum up an average number of 10 families per year enrolling in the project. This even makes a pre-post-study that requests an *n* of 30 participants hard to achieve.

### CONCLUSIONS

The project's concept has delivered an optimal performance in practice. Both parents and children perceive the project as a kind of shelter, where they

- are allowed to be as they are

- don't have to explain themselves

- meet others in similar situations

- deposit their sorrows

- have a first port of call for any problem

- experience a hiatus from the situation at home

- experience a time of carefreeness

- find friends

All families value this shelter as a copious relief.

### STUDY STRENGTH AND LIMITATIONS

The purpose of this study was to describe the participants' experiences with the project and to evaluate the intervention's impact on the children. To our knowledge, no other study has had a focus on a young carers group's effectiveness. Thus, there are no direct studies to support or contrast thes findings. The sample size of five children, four

parents and four staff members is a small group for generalization, but it is a suitable sample size when doing problem-oriented interviews.

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## COMPETING INTERESTS

The authors declare that they have no competing interests.

## AUTHORS CONTRIBUTIONS

JgS carried out the data collection and analysis, and wrote the manuscript. SS carried out the interviews with the staff members and offered an alternative perspective during the analyzation and interpretation process. SM, JgS and WS developed the study design and revised the manuscript critically for important intellectual content. All authors read and approved the final manuscript.

## ABBREVIATIONS

German Federal Ministry for Education and Research (Bundesministerium für Bildung und Forschung)

German Democratic Republic

Health-related quality of life

Multiple sclerosis

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