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Design of a Self-Management Program for Children Aged 6–12 Years with Type 1 Diabetes Mellitus at the Community Hospital Herdecke, Germany

Bettina Berger[a,b] Dominik Sethe[a,b] Dörte Hilgard[c] David Martin[a] Peter Heusser[b,d]

[a] Chair for Theory of Medicine, Integrative and Anthroposophic Medicine, Witten/Herdecke University, Herdecke, Germany;
[b] Institute of Integrative Medicine, Witten/Herdecke University, Herdecke, Germany;
[c] Community Hospital, Herdecke, Germany;
[d] Senior Professorship for Medical Anthropology, Witten/Herdecke University, Herdecke, Germany

Keywords
Self-management · Type 1 diabetes mellitus · Children · Health enhancement · Patient-centered care · Evaluation of a complex intervention · Curriculum design

Summary
Background: Children with type 1 diabetes mellitus (T1DM) must replace lacking endogenous insulin by daily insulin injections or insulin pumps. Standards of treatment include educational programs enabling self-management. The program 'Herdecker Kids with Diabetes' (HeKiDi) is based on an anthroposophic understanding of the human being and intends to provide an individualized, patient-oriented approach to developing diabetes-related and comprehensive human competencies. **Aim:** Analysis of the HeKiDi program for children (6–12 years) with T1DM as the first part of an evaluation of a complex intervention. **Methods:** Ethnographic approach, following the Consolidated Criteria for Reporting Qualitative Research (COREQ), including field observations and interviews with responsible persons, content analysis of materials for determining the structure and the curriculum, presented according to the Template for Intervention Description and Replication (TIDieR). **Results:** The curriculum follows the standard but adds a learning circle between the child and the therapeutic team comprising 3 stages: (1) perception of the abilities and needs of the individual child supported by adult mentors themselves suffering from T1DM, (2) reflection within the therapeutic team, and (3) daily feedback to the child. **Curricular Learning Objectives:** Children feel recognized and supported in their individual developmental and diabetes-related competencies and develop motoric, artistic, communicative, and social skills to strengthen their self-efficacy and to understand T1DM as a lifelong awareness process. **Conclusions:** The curriculum including its associated learning goals and methods was presented. The program was explained and shown to be reproducible. Whether this program truly leads to better outcomes in regard to self-efficacy and hemoglobin A1c (HbA1c, glycated hemoglobin) and how parents and children perceive this will have to be assessed using a comparative interventional study.

Schlüsselwörter
Selbstmanagement · Typ-1-Diabetes mellitus · Kinder · Gesundheitsförderung · Patientenzentrierte Versorgung · Evaluation komplexer Interventionen · Curriculum

Zusammenfassung
Hintergrund: Kinder mit Typ-1-Diabetes mellitus (T1DM) müssen fehlendes körpereigenes Insulin durch tägliche Insulininjektionen oder Insulinpumpen ersetzen. Zu den Behandlungsnormen gehören Bildungsprogramme, die ein adäquates Selbstmanagement ermöglichen. Das auf einem anthroposophischen Menschenbild basierende Programm «Herdecker Kids mit Diabetes» (HeKiDi) soll ein individualisierter, patientenorientierter Ansatz sein, der sowohl diabetesbezogene als auch allgemein menschliche Kompetenzen entwickelt. **Ziel:** Analyse des HeKiDi-Programms für Kinder (6–12 Jahre) mit T1DM als erster Teil der Auswertung einer komplexen Intervention. **Methoden:** Ethnographischer Ansatz gemäß den COREQ (Consolidated Criteria for Reporting Qualitative Research), einschließlich Feldbeobachtungen und Interviews mit verantwortlichen Personen, Inhaltsanalyse von Materialien zur Bestimmung der Struktur und des Curriculums, präsentiert nach TIDieR (Template for Intervention Description and Replication). **Ergebnisse:** Das Curriculum folgt dem Standard, fügt aber einen Lernkreis zwischen dem Kinder- und Therapieteam hinzu, der aus 3 Stufen besteht: 1) Wahrnehmung der Fähigkeiten und Bedürfnisse des einzelnen Kindes, unterstützt von erwachsenen Mentoren, die an T1DM leiden, 2) Reflexion innerhalb der therapeutischen Teams und 3) tägliches Feedback an das Kind. **Curriculare Lernziele:** Kinder fühlen sich in ihren entwicklungs- und diabetesbezogenen Kompetenzen wahrgenommen, entwickeln diese sowie motorische, künstlerische, kommunikative und soziale Kompetenzen, um ihre Selbstwirksamkeit zu stärken und T1DM als lebenslangen Bewusstseinsprozess zu verstehen. **Schlussfolgerungen:** Das Curriculum wurde einschließlich der damit verbundenen Lernziele und Methoden vorgestellt. Das Programm wurde erklärt und reproduzierbar gemacht. Ob dieses Programm wirklich zu besseren Ergebnissen in Bezug auf Selbstwirksamkeit und Hämoglobin A1c (HbA1c, glykosyliertes Hämoglobin) führt und wie Eltern und Kinder dies wahrnehmen, muss mit einer vergleichenden interventionellen Studie beurteilt werden.

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Fax +49 761 4 52 07 14
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Dr. Bettina Berger
Chair for Theory of Medicine, Integrative and Anthroposophic Medicine
Witten/Herdecke University
Gerhard-Kienle-Weg 4, 58313 Herdecke, Germany
bettina.berger@uni-wh.de

Introduction

Type 1 diabetes mellitus (T1DM) is the most common metabolic disorder during childhood. According to the latest estimates, there are around 25,000–30,500 children and adolescents younger than 20 years with T1DM in Germany [1]. Despite numerous technical aids (blood glucose meter, insulin pumps) and structured educational self-management programs leading to a steep increase in overall life expectancy, this remains far behind that of non-diabetics (up to 12 years, according to an analysis of nationwide diabetes registers in Scotland) [2]. In addition, a dependency on lifelong insulin substitution remains, with numerous organizational, physiological, emotional, and social issues of everyday life.

In the S3 guidelines of the German Diabetes Association (DDG), insulin therapy is placed at the center of treatment [3]: 'Insulin therapy is (...) the central topic of a structured treatment and educational program for children and adolescents with type 1 diabetes [4, 5]. During the structured initial training, patients, parents and possibly further guardians should be enabled to carry out insulin therapy independently as part of their daily routine.' Approximately every 2 years, children should be given a refresher course in order to meet possibly modified requirements for blood glucose self-monitoring (BGSM). Structured and evaluated educational material and curricula are available in German for preschoolers, children of elementary school age, adolescents, and parents of children with diabetes (e.g., [6–8]).

The Training Program for Children and Adolescent with Diabetes Mellitus at the Community Hospital Herdecke, Germany (HeKiDi)

The program 'Herdecker Kids with Diabetes' (HeKiDi) is accredited by the DDG as a therapeutic and educational institution (as pediatrics stage 2); it treats around 400 children per year in various formats. The pediatric diabetology at the Community Hospital Herdecke constitutes an important center for children and adolescent diabetology in Germany. The educational program is based on an anthroposophically extended conventional treatment program that places its focus comprehensively on the physical, emotional, social, and personality-related development of patients, with BGSM embedded therein. The HeKiDi constitutes age-related basic treatment programs for preschool children, school children, adolescents, parents and siblings, with follow-up interventions (fig. 1). Within this publication, we will focus on the 1-week basic program for school children (6–12 years).

To date, the effectiveness of the program has not been scientifically evaluated. Only a single case study has been documented: Despite intensified insulin therapy, sufficient glucose control could not be achieved in a 10-year-old girl in standard settings. This became possible using a therapeutic approach within the framework of the HeKiDi focusing on an integrative treatment tailored to the girl's individual situation [9].

The Need for a Complementary Patient-Centered Training Program

For decades, the understanding of T1DM as a disease has been based on a primarily somatic disease concept: Endogenous insulin must be substituted, and for this purpose, one needs diabetes-related knowledge and self-management-related skills [10]. Concerning the patients' perspective, the very first meta-ethnographic synthesis already referred to qualitative studies that pointed to the challenges to a person concerned with establishing a good balance between the necessity of diabetes control and the establishment and maintenance of an appropriate quality of life [11]. In addition to the tasks of normal development, these children also need to integrate their diabetes with its daily management challenges into their self-perception and body image [12]. Also, a higher risk for

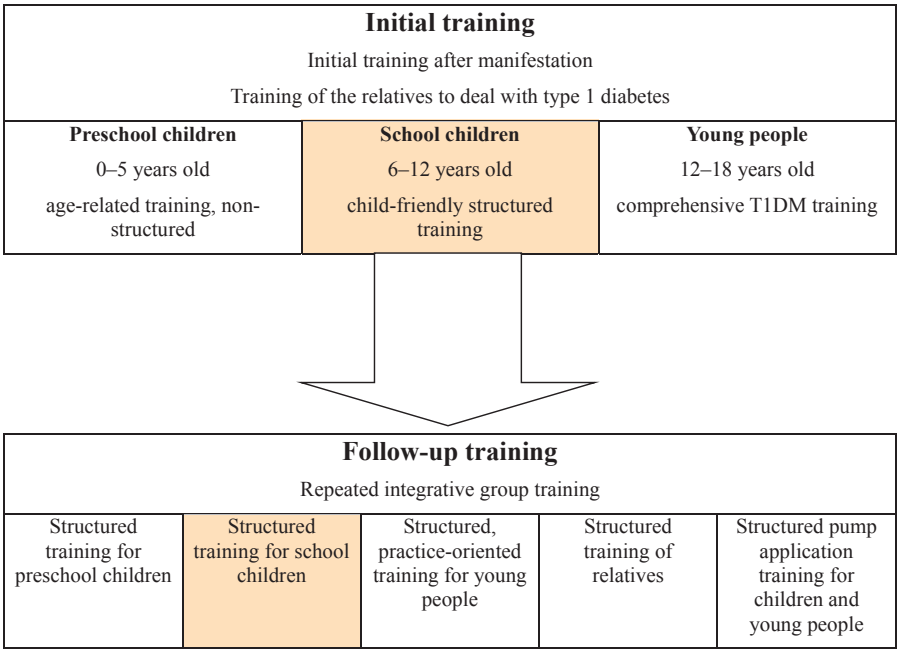

Fig. 1. Structure of diabetes education in Germany. The content of the current publication is marked as blue fields in this scheme. Adapted from [55].

the development of various mental and other disorders points towards the preventative relevance of emotional and social dimensions in children and adolescents with T1DM, for instance, a higher risk of developing depression, eating disorders, or a substance abuse disorder [13, 14].

Parents of children with diabetes increasingly ask for complementary and alternative medicine (CAM) interventions. They want to avoid the complications of T1DM and wish to increase the quality of life of their children [15, 16]. Analyzing the overall reasons of why patients want to be treated within a setting of complementary medicine, we also find the wish to be supported in personal development, including physical, emotional, and social dimensions as well as the self-dimension, and to have a good doctor-patient relationship [17].

Can HeKiDi serve these needs?

Evaluation of Complex Interventions

An answer to this question can only be given within the methodological framework of an evaluation of a complex intervention [18]. Training, in all of its many forms, is usually complex since a number of interacting factors (e.g. training content, methods and qualification of the teaching staff) come together and contribute to the training's overall effectiveness. Thus, the patient-relevant endpoints of the intervention as a whole have to be assessed. In recent years, various concepts for the evaluation of complex interventions have been developed. Savage et al. [19] speak of a whole 'science of intervention development'. Mainly, a stepwise process is recommended as a frame for evaluation, including the development of the theory of the intervention, the piloting of the intervention, the interventional study, and the implementation of the intervention [18]. As described by Fonnebo et al. [20], many CAM interventions were first realized in practice, and only afterwards researchers started to identify the underlying concepts and evaluated their effectiveness and efficacy. Although the HeKiDi program has been established for years [21], beside the standard curriculum according to DDG guidelines, no clear description of the extended program (including learning objectives, methods and material) exists which could be evaluated. For our study, we chose the following steps: (1) presentation of the curriculum, (2) development and validation of an appropriate outcome measure, (3) the interventional study, and (4) implementation.

Research Question

The aim of the first phase of the evaluation of a complex intervention was to describe the design of a self-management program for children aged 6–12 years with T1DM at the Community Hospital Herdecke (HeKiDi), analyzing the main learning aims and relevant structures of the already existing program within the ongoing practice.

Methods

We chose ethnographic approaches – which are increasingly common in educational research – as a suitable method for identifying the learning aims of the therapeutic team, including curriculum and structures [22–25]. In order to structure, analyze and present the complex intervention, we used the guidelines of the public Template for Intervention Description and Replication (TIDieR) [26], which is increasingly used to describe complex interventions [26–35]. For quality assurance of qualitative research, we followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) [36].

Data Acquisition

For the analysis of the already existing training program, we carried out participating observations (using field notes) and interviews based on a semi-structured interview guide in regard to training contents and intended objectives, as well as applied methodologies of the HeKiDi.

Participating observations: We collected observations from different staff members (B.B., D.S.) using field notes to gather data during the children program in order to discover hidden, i.e. not explicitly communicated, structures.

Sample for interviews: We involved the different professions within the team, following the concept of saturation. Nine interviews could be implemented between March 2013 and August 2013, including the leading diabetologist, the diabetes consultant, the social consultant, the art therapist, a carer, and further team members. The interviews were carried out by D.S. and took between 12 and 88 min (55 min on average). Interviews were recorded and transcribed verbatim.

Interview guideline: The interview guideline was developed according to the published quality requirements of the professional associations [37].

Data analysis: For the evaluation of the interview transcripts, we used the content analysis method following Mayring [38], with a complementary open design of the categories [39].

To develop the categories, we used the software MaxQDA for qualitative study data and inter-professional interpretation groups (including people from medicine, cultural sciences, economics, psychology, and medical anthropology), within the framework of research workshops at the Community Hospital Herdecke and in individual work. The evaluation categories were based on the DDG quality requirements for training programs. The citations on which the curriculum descriptions were based were referred to as [X1–00–000], designating the respective interview and text lines as documented in MaxQDA. These original quotes [X1–00–000] were accessible to both researchers (B.B., D.S.). Furthermore, the field notes and instruction documents for intervention participants were analyzed.

Ethics

The ethics committee of the Witten/Herdecke University obtained ethical approval. (no. 86/2012, May 9, 2012). All interview partners were informed about the intention of the study by an information sheet and each interview partner gave their written informed consent.

Results

Description of the Intervention (According to the TIDieR Guidelines)

Name of the Intervention

'Herdecker Schulungsprogramm für Kinder mit Typ 1 Diabetes mellitus (HeKiDi)' – Training program for children and adolescents with type 1 diabetes mellitus.

Theoretical Rationale

– The training program is based on the anthroposophic view of human nature and uses Waldorf-pedagogical concepts for its implementation. The anthroposophic treatment concept is seen as a humanistic extension and not as a substitute of or op-

position to conventional medicine [40]. Underlying this is the idea of a systemic understanding of the human being as an organization of 4 discernable domains: (1) the physical body with its material parts and structures, (2) organismic life processes with their holistic and autopoietic forms of self-organization, (3) the soul with its emotional and experiential inwardness, and (4) the spiritual self or innermost individuality with its faculty of rational cognition, insight, and self-determination. According to anthroposophic concepts, the specifically human potential for self-efficacy and self-management is a deliberate function of this spiritual self. These 4 elements intricately interact with one another and are thus passively affected or actively involved in practically all processes of health and disease. Each one of these 4 levels is taken into account within the framework of a person's medical history, and in therapy they are differentiated. Thus, it is important that each level is sufficiently functional since the processes of these levels are mutually interdependent. The physical level is a prerequisite for the processes of the organic entity, which in turn is a prerequisite for the functioning of the soul, and this in turn for the deliberating self, as one can observe in the psychophysiological development of the child. In turn, as evident from the psychosomatic field, soul and spirit affect the organic whole and the physical levels [40–42]. In an anthroposophic understanding, this means that all 4 domains must be accounted for in health promotion, prevention, and treatment.

– *The importance of middle childhood for psychophysiological development:* The training program for children between 6 and 12 years is addressed to children in their middle childhood. Based on its specific anthropological status, this age has been labeled as a relevant period in the course of human development [43]. Once children have completed a major part of their physical development, during middle childhood the focus of their development is on the acquisition of necessary cultural technologies (reading, writing, and arithmetic), and especially on the acquisition of emotional and social competencies. As a result, the phase of middle childhood is described as a period of high vulnerability during which endogenous and exogenous factors interweave: Physiological modifications (such as hormonal and genetic changes) are accompanied by a higher sensibility towards the environment and thus produce an increased responsiveness towards the social surroundings on the one hand, whereas on the other hand – and at the same time – children increasingly experience inner boundaries in relation to adults they had admired, a process which can result in an overt or covert dissociation from adults. A previously perceived unity within the social environment begins to vanish, a process that can be accompanied by considerable, but not always conscious, inner insecurity. Within Waldorf education, this change is also labeled as 'Rubicon', a term coined by Rudolf Steiner; according to Steiner's psychophysiological investigations, this change marks a crucial transition in the psychophysiological course of self-development. The adult counterpart has an important function of accompaniment throughout this Rubicon phase since, especially during this time, the child requires an adult role model in order to develop his or her own orientation after leaving the childhood 'paradise' [44].

Description of the Intervention

– *Instruction of the necessary educational content for the T1DM management:* Based on the requirements of the DDG, the instruction and formation of diabetes-related, action-relevant knowledge, skills, and capabilities present an important part of the curriculum. To this purpose, the underlying curriculum by Lange et al. [4] is applied within the HeKiDi curriculum.
– *Extension of standard educational programs by accounting for the child's comprehensive development:* The HeKiDi educational program addresses not only the diabetes management but also the child's needs on all relevant developmental levels. This includes the development of emotional and social competencies as well as the domain of inner self-development and self-determination. The issues of self and self-development have a special relevance for T1DM in the framework of the HeKiDi in that – according to the concepts of anthroposophic medicine – the spiritual self exerts its agency on the psychological level as willpower in thinking, emotion control, movement, and action, and on the physiological level as a coregulator of metabolic processes, especially with regard to blood glucose regulation. For example, in case of BGSM, the child has to learn the bodily function of insulin devices and BGSM and to understand the body functions of blood sugar regulation. He or she also has to understand the functional aspect of permanent changes of blood sugar values during the day as a dimension of their living and acting organism. On the emotional level, the child has to develop competencies in perceiving blood sugar level information without reacting emotionally and to maintain the ability to act appropriately. Within the self-dimension, the child has to decide on taking actions (e.g., to eat something) *before*, e.g., playing football, to prevent the development of hypoglycemia. Thus, the promotion of a harmonious and encompassing self-development and the long-term training for self-agency and willpower are important elements of the HeKiDi. This includes art therapies and various movement activities. These are not only relevant in regard to the physiological diabetes management (movement) but also take on an independent function in regard to the development of willpower (physical units) as well as emotional competencies (art units) and social competencies (evening circle or sharing and celebrating relevant daily events together), respectively. The method of the training program is oriented towards a Waldorf educational style [45]. The day is – as far as it is appropriate – divided into a cognitive section, a creativity section, and a movement section (fig. 2; 1-week scheme). In case of therapy needs not covered by the 'routine' program, further interventions can be integrated within the curriculum, e.g., eurythmy therapy, psychological counseling including both parents and children, and, if necessary, a recommendation for a residential psychosomatic treatment.

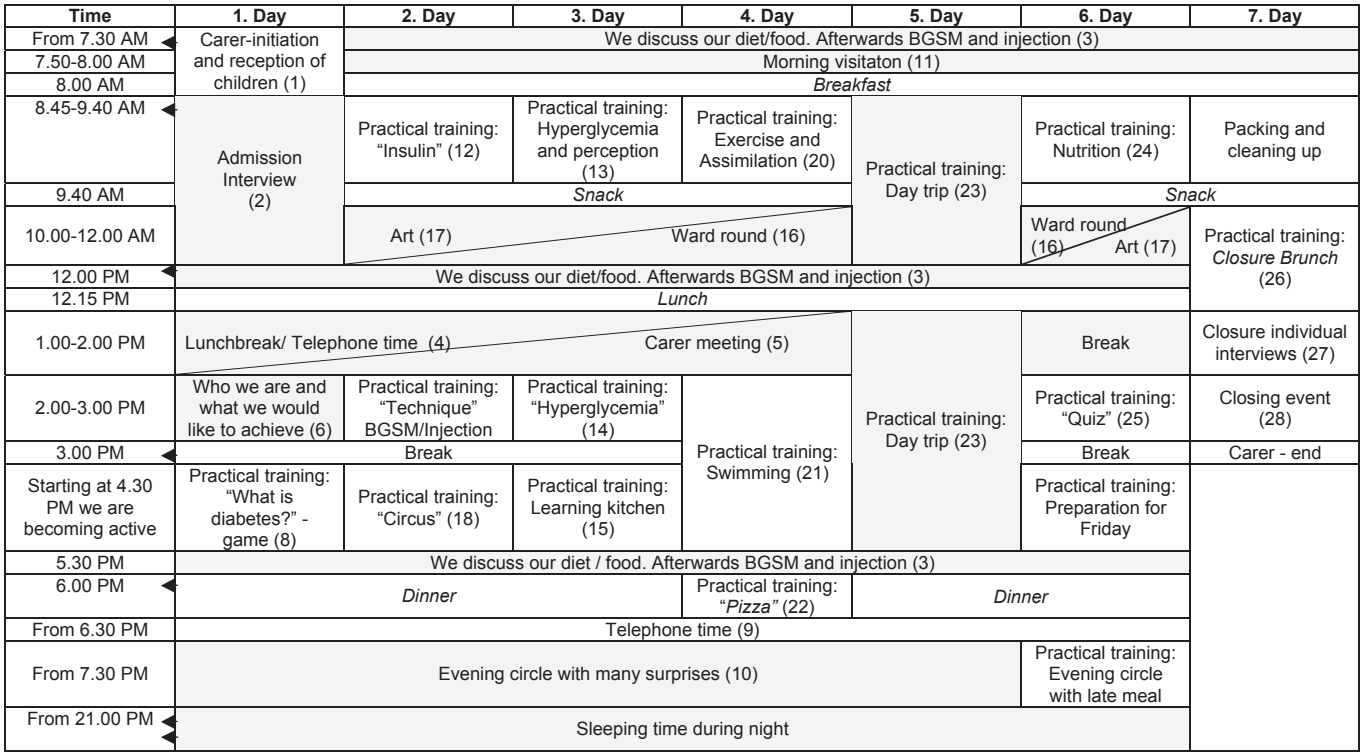

Fig. 2. Sample schedule of a training week of the Herdecke training program for children (6–12 years) with T1DM. The areas highlighted in grey refer to units where observation and perception of the children are the main focus; in the white areas, primarily knowledge, abilities, and skills are conveyed. The black triangles in the first column indicate the times of blood glucose measuring. T1DM = Type 1 diabetes mellitus; BGSM = blood glucose self-monitoring.

– *The role of the adult:* Within the framework of the HeKiDi, children are actively accompanied during the educational program by adult carers who themselves suffer from T1DM. Thus, trainees can witness the way an adult has succeeded in coming to terms with T1DM. These carers accompany children through the program and reflect with them their behavior in everyday life (during blood glucose readings, insulin injections, and during their romping around and playing and in dealing with hypoglycemia), but also in regard to the childrens' social, emotional, and motoric competencies. In this way, the carer serves as a role model. The carers report their perceptions to the therapists and physicians during daily meetings.

Applied Methods, Materials, and Procedures

Waldorf education focuses on the continuous 'actual encounter between the personalities of the educators and their pupils in order to develop creative solutions based on observations, as is required by the particularity of the individualities involved and their living conditions' [46]. To create these opportunities, the learning circle has been established as a structure that allows personal encounters (see the section 'Degree of Individualization' below).

The method is adapted to the needs of the children. The children should get the opportunity to have their own experiences as far as possible and to develop a close relationship to the contents of the program. Thus, age-related methods such as games, storytelling, movement, and specific forms of art, sports, practical trainings and exercises are chosen. The daily rhythm follows the Waldorf concept of education, i.e. to use one-third of the available time for cognitive teaching, one-third for the development of emotional and social competencies, and one-third for the empowerment of the will using sports and movement. Details of the methods are listed within column 5 (Methods and material) of the Online Supplementary Table (*www.karger.com/?DOI=479532*).

Staff Qualification

In line with the guidelines, training is offered through a team of pediatric diabetes experts consisting of pediatricians who also hold qualifications in pediatric endocrinology and pediatric diabetology, 2 diabetic counselors representing the DDG, 1 dietician assistant or 1 ecotrophologist, 1 psychotherapist, and an educator. During the HeKiDi program, the school team is extended by the inclusion of the T1DM-affected carers. Additionally, art therapists with an anthroposophic art therapy education, adventure educators, eurythmy therapists, and a psychiatrist for children and adolescents are added to the team. All team members will have taken part in an introductory seminar in the HeKiDi program.

The Type of Intervention

The HeKiDi is offered as a group-based, additional training program for at least 10 children, including elements of face-to-face contact (daily visits). Carers work with small groups of at least 4 children. The program is based on a structured curriculum, as shown in the Online Supplementary Table (*www.karger.com/?DOI=479532*). This table presents information concerning the

Table 1. The main learning aims of HeKiDi

	Children learn ...	Individual examples of what children were able to learn during the week
Self-dimension: activation of the self and self-development	... to take on more and more responsibility for the BGSM (in relation to the age) ... to use relatives, friends, and siblings as social resources ... to assess whether help is needed ... to understand T1DM more and more as lifelong awareness process ... to handle blood glucose levels easily and inconspicuously ... to develop self-efficacy in relation to the personal development	– blood glucose self-management when staying alone overnight with friends – to persuade the parents and obtain permission to participate in class trips – to ask the brother for support during a football game (to be reminded of BGSM)
Emotional dimension: development of emotional competencies	... to activate zest for life (enjoyment of singing, sports, swimming, playing, artistic games) ... to develop the ability of self-expression ... to develop self-efficacy in art ... to develop communicational skills	– to enjoy swimming without an insulin pump – to talk about fears of hypoglycemia during artistic games – to talk with pleasure about successful BGSM – to talk with parents about the wish to play football and to find solutions – to enjoy the self-made present for the grandmother
Dimension of life: development of life forces and autoregulatory processes	... to structure the day rhythmically ... to perceive the body and its needs ... to use sports/movement to support blood sugar regulation ... to turn BGSM into an embedded habit	– to identify body markers for hypoglycemia – to recognize well-being in the normal blood sugar range – to tolerate sometimes high blood sugar values without anger or anxiety
Physical dimension: substitution of insulin	... to handle insulin devices ... to use insulin appropriately ... to measure blood sugar levels ... to adapt the insulin dosage ... to estimate the composition of nutrition	– to learn to inject oneself – to understand the blood sugar values – to reduce the insulin dosage before sports – to be able to eat a big pizza without blood sugar problems

HeKiDi = Herdecker Kids with Diabetes; BGSM = blood glucose self-monitoring; T1DM = type 1 diabetes mellitus.

intervention learning aims, content, method, and materials resulting from a qualitative content analysis of interviews. The main learning aims are described as follows (table 1): Children learn to feel recognized in their developmental and diabetes-related competences; they develop motor, artistic, communicative, and social skills to strengthen their self-efficacy and to understand T1DM as a lifelong awareness process. We differentiate further details in table 1, with several subaims that relate to the basic anthroposophic concept of the human being with its 4 dimensions of the physical, organismic life, soul (emotions), and spirit (self). The examples in column 2 (table 1) show what children can achieve after attending the course, as reported 1 week later by staff members.

Structural, Basic Parameters and Frequency of the Offer

The educational training of children and adolescents at the Community Hospital Herdecke is part of several blocks of a (minimum) 1-year-long personal doctor-patient relationship (fig. 1). It is grouped into training sessions for the parents of children aged up to 6 years, sessions for children aged 6–12 years, and for adolescents aged 13–18 years. The complex program is completed by special trainings on insulin pumps and follow-ups for each program. Additionally, annual training courses are offered to the non-affected siblings. This training for children between 6 and 12 years takes place twice a year. After the first diagnosis of T1DM, parents and children receive an initial training. This usually takes place in an individual manner immediately after the diagnosis. A new basic/bolus insulin adjustment is usually available as well, as an inpatient program, if necessary. The HeKiDi program addresses children who are supposed to assume an increased independent responsibility for their blood glucose management. The sessions take place in a seminar center close to the Community Hospital Herdecke. As an aspect of health-oriented interventions, even the learning environment for the children should be healthy and should allow for free movement and healthy experience, as far as possible. During the training, the children are only formally admitted as inpatients of the hospital. A training room, a consulting room, a separate room for measuring and injecting, and a community dining area are available. The gym, open areas of the hospital, and the art therapy rooms can be used throughout the length of the program.

Degree of Individualization: The Individual Learning Circle

In relation to the degree of individualization, a core principle of HeKiDi could be identified as a part of the curriculum, resulting in different structural aspects: the learning circle of HeKiDi (fig. 3). This circle is implemented in the daily routine and contains 3 aspects. We call this circle the triad of perception, reflection, and feedback/therapeutic action.

1) *Perception:* The child will be perceived in detail through comprehensive medical history taking, including social behavior and emotional states, and an investigation of his/her current relevant needs, from both the child's and the parents' perspectives [47]. A treatment contract between the child, his/her par-

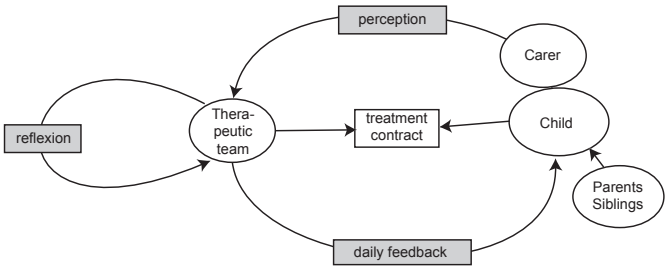

Fig. 3. The learning circle of HeKiDi.

ents, and the doctor will be established. During free play, the child's blood glucose awareness is observed (e.g., perception of hypoglycemia, preventive sugar intake, BGSM) and accompanied or supported (4 children per carer). The sample time schedule depicts the way in which the perception of the child plays a central role (fig. 2).

2) *Reflection:* The carers', therapists', and doctors' observations for each individual child are shared, discussed, and reflected during lunchtime and considered overnight. The interprofessional group (including medical, developmental, artistic, motor perspectives) presents the possibility of developing child-specific intuitions – a central aspect of Waldorf education.
3) *Feedback:* The following structural elements are used to give feedback to the children:
   - individual daily visits (Online Supplementary Table (*www.karger.com/?DOI=479532*), no. 16) (30 min) with the pediatric diabetologist, to monitor the implementation of the treatment contract and, if necessary, its adjustment;
   - the format 'evening circles with many surprises' (Online Supplementary Table (*www.karger.com/?DOI=479532*), no. 10): children get feedback about successful progression in the development of new competencies;
   - the presence of carers during daily activities.

The learning circle is relevant for children in middle childhood, when they have to assume more and more responsibility for themselves but need an adult role model to learn from.

Discussion

The aim of this study was to explain the HeKiDi training program for children and adolescents with T1DM. The main aspects could be described in detail and are summarized as follows:

- The training program conveys the guideline-relevant educational contents to enable children to independently handle everything related to T1DM. In doing so, however, the program is geared toward each individual personality.
- This aim is specified by learning aims oriented to the child's (and parents') needs regarding the diabetes-specific issues and also, beyond these, to developmental, psychological, social, or other needs, and achieved via specific contents of the curriculum.
- A unique structure allowing the implementation of this individual approach is implemented: the circle of perception, reflection, and feedback. This process initiates a social learning process appropriate to the needs of children in the middle age of childhood. It enables children with a chronic disease to learn, step by step, to take over the self-guidance on their own lives.

Compared to the international debate concerning educational programs in diabetes education, many other interventions have been developed and evaluated. However, few programs seem to address psychosocial indicators [48].

Other papers deal with the demands of new health concepts, complaining that our patient education programs are still focused only on disease management and do not include salutogenetic concepts [49]. By focusing on the normal developmental needs of the child, the HeKiDi program can offer health-oriented interventions related to these growing demands. Clarifying age-related responsibilities for different tasks in relation to T1DM self-management and raising awareness of the developmental needs of the child are very important aspects of a health-oriented approach: What the child can and will achieve is the essence of this education. The challenges a family faces in adjusting to developmental changes in patient and family roles in a T1DM context have been discussed only recently [50]. Within the HeKiDi program, the awareness of family members and their understanding of changing roles is a central aspect of the individual treatment approach. Thus, the program intends to fulfill basic aspects of patient-centered care, as described by Rathert et al. [51]. Patient-centered care has been increasingly in demand within the last 20 years [52], i.e., a form of medical care that includes respect, perception, and inclusion of an individual patient's situation, needs, preferences, and worries. In relation to diabetes care and the lack of interventions empowering and supporting patient needs, Anderson and Funnell [53] described the difficulties in implementing patient-centered interventions that support patient empowerment within clinical settings. One main barrier was that many medical professionals demonstrate an attitude that does not lead to enabling patients to take responsibility for their own health. This program might be able to overcome this barrier by engendering an attitude and understanding of the human being as a spiritual-mental being capable of self-knowledge. The discerning person can also be conceived as an 'embodied subjectivity' which, by his/her mental activity, interacts with its own life and its surrounding environment [54]. This understanding of human beings might be especially relevant to persons with T1DM who are forced to use their mental capacity for insulin substitution.

Chances and Risks of this Program

The team members are very much involved in the perception of each child. The program might be a challenge and quite demanding for people not used to having contact with children in such an intimate manner. It requires the willingness of the team members to commit themselves. The extent to which team members are satisfied with their work and how well they manage team problems should be the next step in evaluation. Also, how to include carers as non-professional team members must be solved by any institution offering this program.

Limits of the Study

This paper only describes the current practice of education of children with T1DM within HeKiDi. Children and parents have not yet been included in the program evaluation. The evaluation of the interventions described in this publication will be the next step. The question still remains as to how far this program can truly lead to its intended promotion of self-agency, self-management, and self-efficacy across the whole spectrum of patient cohorts, especially since the training program is orientated towards the perceived individual needs of the patient. A description of the study protocol of the next step of the evaluation of HeKiDi has been submitted for publication.

Conclusion

The curriculum including its associated learning goals and methods was presented. The program was explained and shown to be reproducible. Whether this program truly leads to better outcomes in regard to self-efficacy and hemoglobin A1c (HbA1c, glycated hemoglobin), and how parents and children perceive this, has to be assessed using a comparative interventional study.

Online Supplementary Material

Online Supplementary Table To access the supplementary table, please refer to *www.karger.com/?DOI=479532*.

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Authors' Contributions

D.H. is a diabetologist with a DDG certificate and head of the training program for children and adolescents with T1DM. The conceptions presented here were worked out on the basis of interviews concerning the curriculum and discussed in detail with her. D.S. is a research associate. He developed the study protocol, designed the interviews and evaluated them together with B.B. B.B. has been affected by T1DM for 40 years. She designed the study, trained and accompanied D.S. during the research process and wrote the draft of the manuscript. D.M. read the publication and made significant contributions to improving the manuscript. P.H. read the publication and made significant contributions to improving the manuscript.

Disclosure Statement

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