

Article

Family Experiences with the Upbringing and Education of a Child with Congenital Malformations, Focusing on the Conditions of an Inclusive School Environment

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Abstract: The birth of a child with congenital malformation and serious illness impacts the experiences of all family members and the educational process, but there are only rare descriptions of such cases in the literature. The aim of this study is to understand better the lived experiences of a Czech family who have a child with congenital malformations with a focus on his education in an inclusive environment. The study is based on van Manen's methodology and autobiographic (or semi-structured) interviews with Karl (19), his mother (46), and his father (49). Data were analyzed for every participant separately: the mother—repeated challenges associated with increasing new health complications, discomfort of son, school support, the future, optimism, and gratefulness; the father—comprehensive support of the son, including all family; Karl—concealment of disability, difficulties associated with disability, participation, school support, relationship with peers, and the future. Based on the results of this case study, for the education of students with congenital malformation and illness, we recommend including parents, healthcare professionals, and school staff in the mutual teamwork; adapting the timetables and spatial arrangements at school; and coordinating the educational process with necessary interventions.

Keywords: inclusive education; pupil; special educational needs; congenital malformation; progressive scoliosis; hip dysplasia; bladder malformation; experience



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1. Introduction

Congenital malformations are single or multiple anomalies of morphogenesis of organs or body parts that occur during intrauterine life [1]. They develop prenatally and may be identified before or at birth [1] or later in life [2]. According to the WHO (World Health Organization) [3], 6% of babies worldwide are born with a congenital anomaly, resulting in hundreds of thousands of associated deaths. However, the true number of cases may be much higher because statistics do not often consider terminated pregnancies and still births. Examples of congenital malformation include developmental dysplasia of the hip (DDP) [4]; anomalies of internal organs such as malformations of the bladder and urinary tract, e.g., obstructive uropathy or bladder entropy [5]; scoliosis of the spine [6], etc.

Treatment of congenital malformations, e.g., DPP, ranges from physiotherapy [7], hippotherapy [8], or orthopedic interventions [7,9] to surgical treatment [2]. Congenital anomalies are sometimes partially or completely surgically solved at an early age, but various negative impacts can also appear in later life [10]. This includes pain [11,12], discomfort caused by compensatory aids [13], restrictions on some routine activities, increased medical intervention [12], or reduced quality of life [11]. In addition, the educational process may be affected by the negative impact on the learner's concentration, increased stress [13], and reduced participation in some activities [14]. Moreover, there are temporary

periods associated with the time of surgical operations and convalescence, or other medical interventions that cause reduced time devoted to learning or studying.

In the Czech Republic (known as Czechoslovakia during the time of communism), some learners with hidden congenital malformations were educated in mainstream schools. However, their special needs were often overlooked or downplayed [15]. Students with severe or visible disabilities were mostly segregated to special schools. After the Salamanca Statement in 1994, the global preference for inclusive education [16] also affected the Czech educational system. The Amendment to the Czech Education Act [17] states that a child with special educational needs (SEN) has the right to education on an equal basis with the others and to appropriate conditions that should be created through convenient support measures (SM). The SM provided in the Czech educational system are divided according to severity into five levels [18]. The decisions associated with the first (the lowest) level of SM are only within the competence of the school, whereas dealing with more serious special needs is based on the recommendations of experts from counseling centers. In the case of learners with congenital malformations, the educational support may involve temporary relief at school, securing a place and time for relaxation, increased caution, and the need for operational planning of teaching, so that the student can gradually learn the subjects in agreement with the individual teachers. In such cases, the support is usually purely within the competence of the school, provided on the basis of cooperation with the pupil's parents, while the personal traits and positive approach of all individual teachers and openness and sincerity of the parents are very important [15].

The benefits of an IE for students with SEN are frequently described in the literature and are connected to participation in normal life activities [19], increased academic gains [20], or to higher chances of the development of social relationships [21]. In contrast, the learners and their parents can face some shortcomings associated with physical, psychological, or personal barriers or a non-supportive system [22,23]. Parental openness in the provision of information to teachers can sometimes be limited because the parents want to protect the learner's privacy. Moreover, they may be influenced by the negative impact of the children's disability on their own life [24] with a potentially devastating effect on the cooperation with school [25].

Another risk can be reluctance on the part of the school. Primarily, learners with hidden congenital malformations are at risk of mistreatment by teachers who are not properly informed or overlook their educational needs. These problems may be caused by the lack of understanding of educational staff concerning the experience of these learners. The understanding of teachers and other stakeholders should consider experiences narrated by pupils themselves and their families. Although experts specialized on pupils with physical and developmental disabilities may offer a substantial amount of knowledge considering the education of these learners, there is also an urgent need for research studies. In the Czech environment, the research focused on understanding the experiences regarding the inclusive education of students with congenital malformations and their parents is completely missing [26]. Additionally, international literature offers only scarce examples of studies on this topic [27], e.g., a study on a learner with Hirschprung disease [28].

The objective of this qualitative study is to examine the lived experiences of a learner with congenital malformations being educated in an inclusive environment, and the experiences of his mother and father. This student had a considerable number of health complications that affected his development and influenced mainly his preschool education. The following research question was identified: "What are the lived experiences of inclusive education in Czech schools of a learner with congenital malformations and his parents?"

2. Materials and Methods

This qualitative phenomenological study was based on Dilthey's philosophy [29]. The analysis was carried out according to van Manen's methodology of lived experience [30], which is an exceptional method that enables the researchers to gain a deep understanding of

participants' experiences associated with inclusive education and its impacts on the learner with congenital malformations and his family. This methodology enabled the identification of the understandable importance of the individual experiences of all participants. Every experience was considered in a broader context together with its reflection after it had been experienced [31]. The research was conducted between 2020 and 2021. It was approved by the Ethics Committee of the Faculty of Education, Palacký University, in Olomouc (6/2019). The details associated with the conditions of the data collection, publication, providing anonymity, etc., were introduced to all participants in the written informed consent that was subscribed by each participant before the research itself.

2.1. Subjects

A secondary school student (at the time of the first interview, in the final year of grammar school, and currently a university student) with congenital malformations and his parents were participants of this study. The student suffered from congenital malformation of the bladder and urinary tract detected prenatally, then DDP, which was detected rather late, and progressive scoliosis that began to deteriorate significantly with his entering the school until undergoing surgical operation at the age of 16. All these health complications influenced both his family life and the educational process. An important role in the educational process was the fact that his disabilities were not obvious at first sight and that there was not a direct impact of disability on the educational process and his ability to learn. The student was educated in a traditional elementary school, followed by grammar school. The first contact with his mother was done by email, where she was asked for cooperation and informed about the aim of the research, as well as about the conditions related to the research process (e.g., allowing access to school documentation, a request for the possibility to involve her son and his father in the research, the possibility to talk to some teachers, if necessary, etc.). The personal and family details are introduced in Table 1.

2.2. Data Analysis

The six-phase data analysis process was carried out according to van Manen's approach [30]. First, a verbatim transcription of the recorded interviews into the program Pages was done (for the sake of clarity, some of the interviewees' statements were slightly stripped of speech incomprehensibilities and carefully modified, so that the meaning and nature of the message remained the same). The analysis was done separately for each participant. The phases of analysis were following:

- "Turning to the nature of lived experience"—the step containing the formulation of the research question.
- "Exploring the lived experience"—the step deepening knowledge about the participants' experiences through in-depth interviews.
- "Reflecting on important themes that characterize researched phenomenon"—the step using the process of thematic analysis that enabled identification of key themes of the studied phenomenon.
- "Describing the researched phenomenon by the art of writing and retelling"—retelling the participants' experiences to visualize the participants' thoughts, feelings, and attitudes.
- "Keeping strong and transparent relation to the studied phenomenon"—a necessity to focus on the research question during the whole process of analysis.
- "Balancing research context by thinking about both the whole context and its parts"—paying attention to the ratio of the overall results to the importance played by the individual parts in the overall structure [30].

The order of individual phases of van Manen's analysis was not fixed, so growing data and emerging topics during the process enabled us to move forward or back as needed [30]. The identification of important themes was done in a three-step thematic analysis [30] that consisted of detailed repeated readings of the text, an explanatory approach, and a holistic approach. Detailed reading provided answers to what the read parts of the text revealed about the studied phenomenon. The explanatory approach

was necessary to find out which statements best identified the nature of the described phenomenon. The holistic approach is based on perceiving the text as a whole with the attempt to formulate the phrase that fully expresses its meaning [30]. The process of the themes' identification required setting codes and then marking the sentences that were related to them. Similar parts of the texts were joined under narrower sub-themes or broader themes to capture the overall impression of each interview. During the analysis process, the number of themes and sub-themes grew. The identified themes described in the following text are supplemented by illustrative statements from participants to provide a clear picture of the results and their background in each participant.

Table 1. The participants' personal and family details.

Parents: Family Role, Age, Number of Interviews	Mother	46	2
	Father	49	1
Pupil with SEN: sex, pseudonym, age at the time of the interview, number of interviews	a boy, Karl, 19 years old, 1		
Siblings-sex, age, SEN, school, family background	<ul style="list-style-type: none"> • two sisters, 25 and 22; without SEN, university. • a complete family living together in a family house with a garden in the suburb of the town—mother, father, three children. 		
Type of school at the time of the interview	grammar school—4th (final) year		
The circumstances of disability	congenital malformation: <ul style="list-style-type: none"> • congenital bladder malformation: repeated operations during 1st 3 years of age. • late detected unilateral (left) congenital hip dysplasia: operation (8th month) partially solved the problem-consequences. • progressive spina scoliosis; 16 years of age: operation/implantation of metal reinforcements on both sides of the spine. 		
Functional abilities/education/support measures	<ul style="list-style-type: none"> • pre-school education: traditional kindergarten, complications associated with insufficient control of urination, continuing until the beginning of elementary education (1st grade). • compulsory education: traditional elementary school, complications associated with worsening scoliosis (supportive corset-pains, discomfort, limited mobility). • grammar school: lameness caused by deformity of the hip + one shorter leg. 		
Present situation	<ul style="list-style-type: none"> • the learner was admitted to the university; he is currently studying to teach biology and geography. • in his free time, he continues to lead a Scout unit. • he has made new friendships, but he also maintains friendly relations with some classmates from his grammar school. 		

3. Results

Although the analysis of the interviews with each participant was done separately, some themes intertwined. Most of the topics were connected to solving the boy's health problems, wherein they were related to the necessary medical interventions, the use of orthopedic aids, discomfort, pain, and rehabilitation. These facts were also reflected in his education and were especially related to informing teachers and school management in order to achieve sufficient support, to meet his special needs, and to create an environment

that allowed him to be educated as smoothly as possible. Table 2 clarifies the overall results of the analysis.

Table 2. The overview of themes in each participant.

Categories/Main Themes	Themes/Sub-themes	Mother	Father	Learner with CM
repeated challenges associated with increasing new health complications	the challenges associated with his health condition family adaptation-learning new skills	✓ ✓	+	
discomfort of the son at school	necessary drills restrictions on some activities experience with pain	✓ ✓	+	+
School—parent cooperation	mutual trust-school vs. parents school support based on close cooperation	✓ ✓	+	+
future	good results opened future success interests and plans for future	✓ +	+	✓
optimism and gratefulness		✓	+	+
comprehensive support of the son		+	✓	
included all family	grandparents and sisters' support mother's key role	+	✓ ✓	+
concealment of disability				✓
difficulties associated with disability		+		✓
participation			+	✓
school support		+	+	✓
peer relationship		+	+	✓

✓—the participant openly spoke about it. +—the participant admitted the importance of it but referred to someone else, who was fully involved in it/or mentioned it marginally, giving examples/or the topic is overlapping with a similar theme of another participant but due to the different points of view, the themes were not joined under one overarching theme.

3.1. Mother

In the case of the mother, five themes were identified: (1) repeated challenges associated with increasing new health complications; (2) discomfort of the son; (3) school support; (4) future—good school results opened future success; (5) optimism and gratefulness.

3.1.1. Repeated Challenges Associated with Increasing New Health Complications

This theme included two sub-themes. The mother of the learner spoke in length about the challenges associated with her son's health condition, due to which she was exposed repeatedly to stress and worries even before the birth of her son. In the prenatal period, his urine accumulated in the abdominal cavity and put pressure on the surrounding organs. Therefore, to rescue his life, he was born early by caesarean section, in the 35th week. After his birth, all attention was paid to the solution of the bladder anomaly and the rescue of the child's life:

“He then actually lay in Motol (the hospital) in Prague, and he'd been taken there the very next day after giving him birth. He got a bladder stoma in Motol and had it for two years, . . . he couldn't use his bladder, nothing. It just kept flowing on its own . . . ”

Unfortunately, this caused the late detection of the hip dysplasia:

“... he actually had the bladder stoma for a long time, and as they were solving the other problems, it was somehow forgotten, or they didn't really solve the hips at all. This was still being addressed here, and then, at seven months, I actually realized that one leg was different from the other, ...”

The bladder solution required five surgical operations within 2.5 years, and the dysplasia, which was detected at seven months of age, required one surgical operation and long-term plastering. The recovery was slow and major surgical interventions were associated with long term hospitalization and were reflected in his delayed motor development.

The operations were successful and solved the anatomic problems but did not immediately solve the functioning of the bladder and urinary tract. He had to learn to control his bladder and urination, which persisted still in his first year of school. With the onset of school, spinal scoliosis began to manifest. The intervention started with physiotherapy, exercises, and swimming, but his condition worsened until the surgery at the age of 16:

“... he got a corset for it. At first, for twelve hours a day; he was eight to nine years old then.” “... they (the doctors) said the spine was just bad. He had serious scoliosis and ... he started to grow a lot at 13 years of age, he just grew fast, it was in that age that he grew tall all at once and his spine made a full S-shape, and suddenly from 20 or 30 degrees it was 50.” “... and when he was 15, they (the doctors) already decided that he would have to undergo surgery, that doing exercise or anything would simply no longer help. Without the corset, he would collapse, he would be kind of crooked. He was given time to grow as much as possible, because when you have the iron bars in the back, then your legs will grow a little, but the spine can no longer lengthen. So he waited until he was 16 to measure at least 170 cm. And suddenly, due to the operation, he had an extra 4 cm in height! The operation did it, the rod that was put in there, the S just leveled up and suddenly he stood up and I said 'you're somehow tall', it was the 4 cm.”

Another sub-theme dealing with the son's health complication was family adaptation-learning new skills. The changing health condition, necessary cooperation with experts and necessary medical interventions required a lot of changes in the family. The surgeries were done nearly 300 km from their place of residence. The family had to adapt to difficult conditions, when they could not see their child for a long time; they repeatedly had to accept the fact that the surgery or another procedure did not bring the expected improvement and the child would be expecting another intervention. With the child's deteriorating condition, the mother had to learn therapeutic interventions, to be able to support her son as much as possible. The need for the process of adaptation repeated.

3.1.2. Discomfort of the Son at School

The theme of discomfort of the learner includes the sub-theme necessary drills, which was associated with the parents' demands needed for improving their son's condition and protecting his health. For example, during the pre-school period and the first grade of school, when he had to learn to control his bladder emptying by will, they had to strictly organize his school day by ordering him regular use of a toilet after every school lesson, to achieve the required hygiene habits. They had strict requirements on him to wear the corset, regardless of any discomfort and pain. Another sub-theme, restrictions on some activities, was associated, for example, with the demands for security after the surgery, etc.

“Then, when he was after the spinal operation, he had to lie down for 2 months, and then he was allowed to sit for only 4–5 h a day” “... Then he was not allowed to do anything at all, no physical activities, sports, he was forbidden to ski, ride a bike, everything, that year.”

Other discomfort was associated with his experience with pain in both post-operation periods and caused by the corset use.

“... they operated on him again at the age of two; he went to that operation four times before it succeeded. Then he had to lie for three weeks, without movement, locked in that

crib, until it actually healed, and then we waited for the first pee. Then it took about half a year for the bladder to regain control, so he was wetting himself within about 2.5 years of age. . . . Now, imagine that he went to school with that (the corset), well... so he always had a T-shirt and that corset, because that corset always cut him all over his body, his whole skin was cut and pressed. So we had to buy him tight cotton under-shirts so that he didn't sweat in it. It had to be changed every day, so that's it."

3.1.3. School–Parents Cooperation

The relationship between the family and the schools was based on mutual and close cooperation with parents. The parents turned to both institutions with confidence, entrusting sensitive data concerning their son, so that the school could meet his special needs and provide the necessary support in his education. Although the family did not co-operate with any counseling facilities and the learner at school did not have an individual educational plan, both the primary school and the grammar school fully met their requirements and provided him with the necessary support. At the request of the boy's parents, they kept all the information secret to protect the pupil from embarrassing situations. In fact, he does not know that teachers were informed, for example, about his incontinence problems or his overall health, up to the present. Everything took place on the basis of the trust and cooperation of the parents with doctors and the school.

In the first grade, the teachers were informed about his condition, and therefore, he was allowed to leave for the toilet, when necessary, during the lessons. In the lessons of physical education, the learner did not do the activities that could be harmful to his hips or spine. After the spinal surgery, the schoolmates were informed about his condition and the school created an undisturbed environment for him to rest:

" . . . after the operation . . . he was allowed to sit for only 4–5 h a day, so the headmaster simply arranged for him a tiny room, where we brought him a mattress, so he went to lie down there every break. He had his own keys, so he could stretch out and give at least a moment of rest to his spine, to relieve it. Well, after that operation, the teacher actually told the kids to watch out for him, not to bang him in the back, and things like that, it just worked completely. . . . The textbooks were arranged-he didn't carry them to school at all, he didn't have to carry it, so he had them double-set, some at home and some at school. I have to say that the headmaster arranged all this for us."

His schedule was reorganized so that he could have a rest after five lessons of sitting. What the mother also appreciated was the barrier-free school that her son attended. Although he was not immobile, the presence of other learners in wheelchairs in the school, in her opinion, spoke also about the expected appropriate approaches of the teachers.

3.1.4. Good School Results Opened Future Success

Despite all the health problems and a high absence from school, the pupil was an excellent student. Currently, he is a student at university and is aiming to become a teacher. His mother spoke about his intelligence, diligence, other character traits, and the range of his interests, as well as the support gained from the school, because thanks to that, together with his parents' support, his further educational path and future career was determined, and the parents did not have to worry about his future. Both parents appreciated the approach of the school headmaster, individual teachers, and also his schoolmates:

"He's going to study teaching, biology and geography. He already leads the kids in the Scouts; he has a group of kids, yeah, so . . . they love him, the kids, and he loves movement. We are an active family, he is used to it, he is trained-so they stretch hammocks between the trees, put shelters over each other and that's it . . . "

3.1.5. Optimism and Gratefulness

During the interview with the mother, there was obvious optimism that accompanied her from the first reports on her son's disabilities. She was aware of the need to find a

suitable solution for each problem. She realized that it was important to be patient and to follow the advice of experts consistently and exactly. In education, she was grateful to the staff of the schools they had worked with and mentioned several times during the interview that the attitude of people was the most important factor, because everything could work if you met willing and empathic people: “... it’s a lot about the people who work there”. She felt grateful for her son’s achievements, associated both with his school results and his physical condition, whereas she considered remaining problems, e.g., his shorter leg or slight restriction of movement to be negligible, compared to what the son and the family had gone through.

“He’s had practically no restrictions since he was 17, after that year he could do anything. When we asked if he could, they (the doctors) said ‘yes, but very carefully’, ... and now he does skiing, cycling, everything—we are used to traveling in the summer, skiing twice in Austria and Italy in the winter and so on, so ... ”

3.2. Father

The boy’s father confirmed most of mother’s or son’s information and added that he personally supported his son too, but at the same time he also admitted that most of the key issues associated with healthcare and education were handled by his wife. For example, even though they visited the schools where their son was educated together, he only accompanied his wife and, unlike her, did not actively participate in any arrangement of providing the necessary support. It was his wife who spoke to the teachers or to the headmaster, she was the one who accompanied her son to the hospital, who learnt the physiotherapy, etc. On the other hand, he found his own role in support associated with the son’s leisure and sports activities, to affect positively his physical and psychological condition, and his overall well-being, or to protect him from any discomfort. He led him to take an interest in scouting, which positively influenced both his leisure and his peer relationships and later impacted his future career: *“We used to go climbing on the climbing wall to support his back muscles, while my wife used to go swimming with him for the same reason”*.

3.2.1. Comprehensive Support of the Son

In connection to school, there appeared two main themes. The father appreciated mainly the importance of the comprehensive support of the son, including mother’s emphasized participation of the school staff, but also multiple support in other fields, e.g., the involvement of Karl’s schoolmates and Scout members, and their effort to support their friend: *“When he was in the hospital in X (a city about 60 km from his home town), his mates agreed and went to visit him in the hospital together. It helped him a lot, and it helped us too”*. This positively influenced not only Karl himself but brought a positive impact on both parents too. It was very impressive to know that he was not indifferent to his peers and that they really cared about him.

3.2.2. Including All Family into Care

Another supportive fact that the father appreciated a lot was including all family members into the care, because Karl’s grandparents’ and siblings’ support and help played an irreplaceable role; especially the parents in law’s: *“My wife’s parents were very helpful and they supported us from the very beginning. It would be much more difficult to overcome it without them”*. However, in connection with the family support, he attributes the largest benefit to his wife, Karl’s mother, who was the organizer, caregiver, lawyer, a nurse, and a mediator between all participants *“It was my wife, who arranged everything. She talked to the teachers, spent time in hospitals and at the doctors with him, transmitted information, learned with him, did therapies and cared for him since his birth.”*

3.3. Karl

During the interview, Karl spoke mainly about his disability and its influence on his school attendance. The six following themes were identified: (1) concealment of disability,

(2) difficulties associated with disability, (3) participation (4) school support, (5) relationship with peers, (6) interests and plans for future.

3.3.1. Concealment of Disability

The learner experienced long-term usage of diapers at pre-school age and then difficulties controlling his bladder function that remained during the first grade of elementary school. Such experiences might have had a negative effect on the child's self-concept and self-esteem. Therefore, the concealment of disability associated with his controlled urination was one of the important topics connected with the beginning of his elementary education. Openly informing the teachers or an accidental urination detected by classmates would have led to his feeling shame and humiliation:

"More or less, the first thing that somehow affected school was those bladder surgeries. The operations took place before starting school, but it was related to . . . my mother would probably describe it better, some hiding of the incontinence. I kind of remember that. That was during the first grade and then it fixed completely."

Later, when the scoliosis of his spine began to develop and his condition worsened and so he had to wear a corset, he tried to keep it secret from his classmates and he wore a corset mainly at home, during the day and at bedtime, at least while it was necessary to wear it all day long: *"I usually wore it hidden under a T-shirt, so no-one knew about it, only my friends. . . . When I was with friends, I took it off, mainly when I already knew I was going to surgery."*

3.3.2. Difficulties Associated with Disability

Most of the surgeries and therapeutical interventions associated with congenital disabilities took place before the beginning of compulsory education. The first difficulties experienced at elementary school were associated with his slight incontinence, the need to not forget to go to the toilet after each lesson and sometimes with the need to go to the toilet during the lesson, or eventually difficulties with occasional incontinence. Wearing the supportive corset was uncomfortable and at times even painful: *"What influenced going to school was that I actually had to wear the corset, . . . When I wore it for a whole day, I was stiff and firm, but it wasn't entirely pleasant. Sometimes there were some abrasions or cuts"*. Sometimes the corset caused him trouble with his arm and hand which tingled and froze and caused difficulties to write. After the operation, he suffered from pain, and it was difficult to remain sitting. By doctors' orders, he was allowed to sit for a maximum of four or five hours. The school headmaster arranged a room for him to have a rest in. He could lay there, but it helped only during the 20 min break before noon and during the lunch break that lasted one hour. Then, he could have a rest during the lessons of physical education because he was excused from them for one year. Sometimes, it was difficult for him to sit still until that break.

3.3.3. Participation

The participation of Karl was not extremely limited, but the exclusion from some activities, e.g., activities in the lessons of physical education, affected him a lot regardless. He experienced huge restrictions, namely a year and a half after the operation of the spine, when he was not allowed to do any sports and did not participate in the ski training course. He enjoyed being very active, and the highest possible participation in joint school and sports activities played an important role to him.

3.3.4. School Support

The learner appreciated that the school that he attended was barrier free and learners with disabilities were not an exception there. Therefore, the attitudes and approaches of the headmaster and teachers were very positive:

“As for the approach of teachers, I have never had a problem. In the first grade, if anything, I don’t even know if the teachers knew about my problem (incontinence), and if so, I didn’t know about it. But I don’t think my mom told them, it was a secret. Well, in the grammar school, I was there after the operation, they completely met my needs, and the class teacher gave the information to the class so that I didn’t get hurt.”

Karl was aware of his needs and did not require anything extra which was not really necessary (e.g., copied materials because of his problems with right arm mainly in subjects requiring lots of writing, for example languages, history, etc.). His support measures were associated, for example, with reduced activities in physical education, to prevent hip or spine damage or pain (e.g., rebounds or contact sports), or the choice of extracurricular activities (e.g., experiential teaching, school trips, etc.). What he really needed was a place where he could lie down, so he got a little room where his parents gave him a mattress to enable his back rest after sitting in the lessons during the first year after the operation.

3.3.5. Peer Relationship

Good relationships with peers, building friendships and positive relations, was important for Karl. He always had friends at school and good relationships both at elementary school and at grammar school. He also had a very nice relationship with younger teenagers as a Scout group leader. According to him, his disability or health problems did not influence his relationships with others: *“It (scoliosis, corset) certainly didn’t bother me in my relationship with friends. The only thing that happened from time to time was that they got hurt by the corset I wore, when we were doing something”*. The relationships built during secondary education have persisted to this day, as the student still leads the Scout unit and maintains a friendly relationship with some former grammar school classmates.

3.3.6. Interests and Plans for Future

As the learner liked leading children in Scouts and working with them, he linked his interests to his future career and decided to become a teacher. With his school results, he was admitted to university, and he had clear ideas about his future aims.

“Now I would like to graduate from the Faculty of Education. I’d actually gone to Scouts since I was about eight years old, and at fifteen I got to lead the children and I actually started to enjoy it somehow. I started to spend more and more time with it, and in the end, I realized that I’d like to teach, and at one of schools I applied for a biology and geography teacher, and I got there. I will study at the Faculty of Science.”

Nowadays, he is a university student and plans to teach geography and biology at elementary school in the future.

4. Discussion

Based on the interviews, specific roles and perspectives of family members were identified. The experience of the mother was connected to the uncertainty followed by repeated health complications. These complications accompanied both parents already in the prenatal period and continued until their son’s late adolescence age. In such periods, a lot of social support (mainly non-formal) helps to cope with serious stressors [24], as we could see in the example of Karl’s parents. Additionally, formal support from professionals, e.g., from teachers, is helpful and appreciated by parents of children with various diagnoses [32–34]. Other themes of the mother were related mainly to Karl’s education. His mother was a key person in the medical care and the education of Karl. She was full of optimism, energy, and willingness to learn new things. Her professional background as a nurse played an important role in the overall care of Karl.

The father dealt mainly with the importance of accompaniment of mother and providing additional support, especially with their son’s free time activities. He led him to participate in sports, to attend Scouts and engage in outdoor activities. The supportive role of fathers is very important in families of children with physical disabilities and illness. On

the other side, fathers do not get as much social support as mothers, especially emotional support from their families and social networks [35]. Moreover, they may easily feel cut off from the care of their child. In the case of Karl's father, there was a private space for parenting, connected mainly to sports and free time activities. Support of Karl's active involvement in numerous free time physical activities with his surroundings had to be of high importance for Karl, considering his love for sports, restrictions with sports and outdoor activities he had experienced in the school environment, and also the fact that such activities may have a positive effect on the self-concept and self-esteem of children, as well as adults [36,37].

Karl dealt with similar themes to his parents. Mainly, his description of difficulties associated with his disability, interests and plans for future overlapped with his mother's narrative. It was obvious that he tried to play down the meaning of some challenges, and he was not open about some topics, e.g., problems with the corset or problems with his hand resulting in writing obstacles. Physical disabilities often manifest in numerous limitations, connected to limited movement, pains, tingling, tiredness, and other troubles, as was described in our study. Scoliosis in adolescents is associated with a disruption in their quality of life and can lead to discomfort, psychological stress, and a negative impact on their self-image [38]. All these psychosocial impacts reflect also in the educational process. Both the learner and his mother pointed to similar impacts associated with scoliosis, hip dysphasia, and the impacts of his bladder anomalies. The theme "concealment of disability" was associated with feelings of shame and trying to hide problems probably challenging his mental well-being and self-concept [39]. Teachers should be aware there may be hidden or not-obvious health complications challenging the educational process of the pupil. The pupils may want to conceal these problems and talking about it may be very sensitive. Therefore, close cooperation with the parents of the pupil is required and not all communication between teachers and parents must be shared with the pupil.

There was a lot of social support that helped Karl and his parents to overcome various difficulties. This support was provided from the wider family, teachers, schoolmates, and peers, etc. The health status of Karl was a challenging one, connected to its worsening over time and the occurrence of new health complications. In this context, Sobotková [40] (p. 81) talks about necessary "resiliency", or *"the family's ability to recover rapidly from a crisis or transient event that has caused changes in family functioning"*. Parents are the closest reference persons, usually best acquainted with the needs of their children, and they are experts in their well-being. In the educational process, they are the most important persons that teachers need to cooperate with. However, parents may be under considerable psychological pressure, because they have to face their child's life complications, e.g., presence of numerous surgeries and other interventions, facing their children encountering pain and discomfort, increased absence from school, and other difficulties [24]. There is a risk that such facts can increase their vulnerability and negatively influence their educational style, using approaches that could cause children's increased dependence on parents, prevent children from natural socializing, and reduce their participation in common activities and interaction with peers [41].

Furthermore, these circumstances may impact the communication of parents with teachers and school staff. Because open communication is one of the most important factors for the successful integration of learners with physical disabilities and illness into the school environment [25,42], teachers should actively support open communication with these families and be aware of potential barriers [25,43]. In the narrative of this family, we could see an example of successful education and integration of Karl into the school environment. It was evident that a high level of social support, and open and sensitive communication was appreciated by Karl's parents and enabled them to provide sufficient support to their son. These parents met a good-minded attitude of teachers and school staff for fulfilling the needs of Karl even beyond a measure that could be required by official normative. There were specific strategies for communicating sensitive issues that had to affect Karl's

self-esteem because of the openness of his parents. However, this openness could only be allowed in the environment of mutual trust and due to the empathetic attitude of teachers.

This study could be considered an example of “good practice” in connection to inclusive education, based mainly on the close cooperation between the family and school. The optimistic approach of the parents, their flexible adaptation to each new challenge, and clear division of their roles in their son’s support contributed to him achieving the highest possible quality of life, socialization, participation in common life activities and independence. Although this study is just an example of one case, it shows that high involvement of parents and willingness of school management and teachers are some of the key factors in achieving sufficient support of a learner with SEN. We are aware of the limitations of this study and the results must be dealt with very carefully, because this research included only one family, and, additionally, learners with congenital malformations represent a very heterogeneous group of learners with different needs. However, van Manen’s analysis in this case made visible some facts that should be taken into account when educating learners with SEN; that is, above all, the need for an understanding and empathic approach of teachers, and in addition to providing organizational support, the need for a sensitive approach to delicate topics in order not to harm the student’s positive self-concept. Sometimes, an approach of the environment based on trust, understanding and willingness can provide more support than officially established measures, and in the Czech educational environment, it is even more important, especially in the cases where support is provided only within the competence of a school.

Limitations of the Study

This study clarifies an issue that has not been sufficiently researched yet, both in the context of the Czech educational system and in the international context. The study was performed according to a rigorous methodology that was designed for the analyses of lived experiences. The transparency and credibility of the results is supported by the statements of individual participants. The limits of the study are associated mainly with its design, because without further research, the results cannot be generalized to a wider population of learners with congenital malformations, nor to learners from different socio-cultural backgrounds. In addition, the conclusions were drawn only on the basis of the data obtained via the interviews, while no other methods of data collection were used.

5. Conclusions

This study depicts the case of a successful upbringing and “a good educational practice”, because despite the serious health problems of the learner, there was no need to set the pupil’s individual educational plan, and yet, both the primary and secondary schools conducted all the necessary steps and support to such an extent that all the special needs of the pupil were fully respected and met. To achieve this, three important steps were defined that helped the smooth course of education and upbringing. The first one was mutual teamwork including parents, healthcare professionals, and school staff, while parents acted as mediators and informants. The second was the flexible adaptation of timetables and spatial arrangements at school, which always had to be adapted to the current situation. The third one was the organization of the educational process with regard to school coordination with necessary interventions. It is clear from this case that the active involvement of parents was very important in all three points above. The roles of both parents were clearly defined; while each of them was fully involved in supporting their son in a particular area, they were also open to support from the extended family. Both parents promoted such approaches that respected only the really necessary restrictions and limitations, which were in addition only temporary, so that support measures were always provided only for the necessary period of time and to the necessary extent. Such an approach led to their son’s independence, positive self-esteem, protected him from self-pity, and developed his potential. Another key point was the willingness and helpfulness of the staff of both schools, especially the class teachers and school headmasters. This barrier-free approach

addressed not only barriers in the physical environment, but mainly the positive attitudes of teachers towards the distinction of Karl's education, his personality, and special needs. Quality communication and cooperation between parents and teachers was essential in overcoming potential challenges caused by obvious, as well as concealed, impacts of the pupil's disability.

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