


# Experiences From a Coaching Program for Parents of Children and Adolescents With Type I Diabetes Developed Through Experienced-Based Co-Design (EBCD)

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## Abstract

Many children and adolescents with type I diabetes (T1D) have difficulties reaching the national treatment goal for HbA1c (long-term blood sugar) which is associated with increased risk for complications. This makes it important to explore what patients and their caregivers describe important in coping with everyday life. The study has been conducted within a pediatric diabetes team in the south of Sweden. The aim was to explore how Experienced-Based Co-Design (EBCD) can be used to identify, test, and evaluate improvement efforts in order to support the family with a child with T1D. A modified variant of EBCD based on focus groups, workshops, and interviews with stakeholders was used. The improvement proposal parental coaching was tested and was appreciated by the participants. The qualitative content analysis of the interviews showed that the coaching program contributed to better confidence and self-efficacy. Both coaches and coachees described that the coaching contributed to better competence and a feeling of hope after attending the coach program. Experienced-Based Co-Design gave an opportunity to explore what's important to improve, based on experiences and needs of several stakeholders.

## Keywords

co-production, parental coaching, diabetes in children and adolescents, self-efficacy, qualitative interviews, Experience-based Co-Design

## Introduction

Type 1 diabetes (T1D) is a lifelong disease, which means that the person or her/his guardian must consider insulin doses relative to food, current blood glucose and activity, 24/7, all year round (1). About 65% of the patients treated in Sweden do not reach the national goal for HbA1c (48 mmol/mol = 6.5%) (2). A high HbA1c level means increased risk for complications (3). Swedish register studies show that poor metabolic control during adolescence is associated with higher risk of microvascular complications as young adults (4) and that there is a correlation between high HbA1c during the first 3 to 15 months after diagnosis and microalbuminuria and retinopathy in early adulthood (5). Studies also show that there is a correlation between good metabolic control and perceived quality of life (6,7). Although much effort has been taken to support the care of children with T1D and improve their metabolic control, it is still not enough. Due to the extensive demands on self-care

when handling T1D, the capacity to take control in everyday life is central.

According to the Swedish Health and Medical Care Act, the quality of care must be systematically and continuously developed and secured (8). Health-care professionals may assume that they know what is best for the patients, which could explain why their efforts sometimes are not enough. Asking patients themselves and offering patients to be

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involved in their treatment should be the first step. This is supported in the Swedish patient law, which describes that health-care professionals should promote patient integrity, self-determination, and participation (9). This is also beneficial to the individual and may provide better resource utilization (10). Studies have shown that patients' perception of participation is not just about being informed but about being involved in decisions about their own care (11). One way to involve the people who have experience of what works in the improvement efforts is described in Co-design, which is based on the fact that people who have their own experience of a subject together highlight a problem and come up with suggestions for solutions (12). People living with a disease are a great resource of knowledge, experiences, and ideas that could be used to a greater extent to develop and improve care (13). Experience-Based Co-Design (EBCD) is a variant of co-design where people with experience of a disease together with health-care professionals develop improvement efforts (14) based on "touch points" which is emotionally significant points. According to Mulvale et al, the EBCD methodology may offer particular advantages in applying patient-centered care (15). Fundamentally, quality improvement underpins an understanding that those directly involved in giving and receiving a service are best placed to improve it, assuming that they are given the right tools and authority to do so (16). The combination of knowledge from health-care professionals and experiences from people living with T1D may create value for everyone involved. Experienced-Based Co-Design has been used in other pediatric contexts establishing collaboration, mutual respect, and understanding in order to improve health-care services (17,18) but as far as we know not pediatric T1D. Therefore, the aim was to explore how EBCD can be used to identify, test, and evaluate improvement efforts in order to support the family with a child with T1D.

## Methods

### Design

The project is based on action research with an interactive research approach (19). A qualitative design using one-to-one interviews, focus groups, and collaborative reflections was used. Action research is a suitable approach since the researcher is involved in the process that is being studied and that the results are taken back to the health-care organization, to achieve further change (20). In this project, the first author worked as a dietician and project manager in the pediatric clinic.

### Setting

This study was conducted at a medium-sized hospital in the southern part of Sweden, serving about 280 children with T1D. Team members from the hospital together with diabetes teams from 2 nearby medium-sized hospitals were involved in the focus group interview.

## Data Collection and Analysis

The project was divided into 5 phases using different data analysis methods with an overview described in Table 1.

### Phase 1. Capturing and Understanding Experiences

In order to gain knowledge about what patients, parents, team members, and school staff (teachers, school nurses, and special resource persons) describe as important aspects when coping with everyday life with diabetes, we invited these participants to focus groups.

The purpose in EBCD is to describe improvement suggestions *together with* those it concerns, in this case parents, diabetes team members, and school staff (21). Invitation letters were sent to all parents of children who had T1D for at least 1 year ( $n = 208$ ) and adolescents between 13 and 17 years and was treated at a regional hospital in the South of Sweden ( $n = 103$ ). The school staff from the same region were invited through a coordination nurse by e-mail. The sampling technique used was convenience sampling (22). Diabetes team members from 3 hospitals in the south of Sweden were invited to participate. Two focus groups with parents, one with school staff and one with team members were conducted at the hospitals. As the adolescents did not register for the focus groups, they were interviewed over the phone instead or interviewed in connection with a scheduled medical visit ( $n = 10$ ). All interviews were recorded and transcribed verbatim.

The interviews were analyzed using qualitative content analysis (23). The purpose was to find out touch points that were described by the participants. First, all texts were read several times to understand more about the essence of the described phenomenon. In the second step, codes that were connected to the purpose were marked. Then, codes were compared and discussed between the authors to merge similar and dissimilar codes to reach a higher order, defined as subcategories. The subcategories were divided into 4 touch points (14), which were close to the original text content (24).

### Phase 2. Identifying Improvement Ideas, Workshop No 1

Parents ( $n = 8$ ), adolescents ( $n = 2$ ), team members ( $n = 4$ ), and school staff ( $n = 1$ ) attended the workshop which was led by the project manager together with a facilitator. Discussions based on the touch points identified in phase 1 took place in 3 mixed groups and post-it notes were used to present the groups' suggestions. The groups came up with several improvement ideas. All ideas were presented for all participants and the groups' task was to prioritize among the ideas. At the end of the workshop, all participants discussed together which of the ideas that should be tested. The groups agreed to prioritize the idea of parental coaching.

**Table 1.** The Phases, Participants, and Time Frame of the Project.

Steps	EBCD phases	Data collection forms	Invited	Participants	Data analysis	Time frame
A	1. Capture and understand experiences	Focus group interviews and individual telephone or one-to one interviews (first round)	n = 208	Parents of children with T1D (n = 16; 5 men, 11 women) Adolescents (n = 10; 5 boys, 5 girls) Diabetes team members (n = 6; 1 man, 5 women)	Content analysis	March-September 2017
			n = 103			
			3 teams <sup>a</sup>			
B	2. Identifying improvement efforts	Workshop No 1.	n = 16	School staff (n = 5; all women) Parents (n = 8; 2 men, 6 women) Adolescents (n = 2; 1 boy, 1 girl) Diabetes team members (n = 4; all women)	Consensus agreement	October 2017
			n = 10			
			n = 6			
			n = 5			
C	3. Testing the improvement effort—coaching program	Recruitment and mediation of coaches and coaches	Unknown <sup>b</sup>	School staff (n = 1 woman) Coaches (n = 15)	Content analysis	October-December 2017
			n = 15			
	4. Evaluation of coaching program	Individual interviews (second round)	n = 10	Coaches (n = 10) 6 coaches 8 coachees	Consensus agreement	April 2018
			n = 15			
			n = 10			
5. Confirmation	Workshop No 2.	n = 10	Coaches (n = 3) Coaches (n = 7) Adolescents (n = 2)	Consensus agreement	April 2018	
		n = 6				

Abbreviations: EBCD, Experienced-Based Co-Design; T1D, type 1 diabetes.

<sup>a</sup>School staff was invited by e-mail by a coordinating nurse in the region, the amount who received this invitation is unknown.

<sup>b</sup>The nurses at the department asked parents if they wanted to participate. The amount asked is unknown.

### Phase 3. Testing the Improvement Effort

The idea of parental coaching was formed as a coaching program tested at the Pediatric department at the regional hospital from October 2017 to April 2018. Experienced parents (note 1) (hereafter described as coaches) were asked if they wanted to be coaches when they were visiting the pediatric department during an ordinary scheduled visit. The parents of a newly diagnosed child were offered a coach. The families were asked during inpatient care of their child or during the follow-up visit at the pediatric department shortly after being discharged from hospital. The project manager handled the mediation of coaches to these parents (hereafter described as coachees). An information sheet for coaches was printed and coaches were recruited by the project manager and diabetes nurses working in the diabetes team. The coaches were instructed to contact the parents who wanted a coach by phone, either by a text message or a call. The coaches did not receive any education or particular instructions, thus the coaching varied between the couples. The instruction was to agree together on how and how often the contacts would take place, and which contact they wanted to have.

### Phase 4. Evaluation

Six of the coaches and 8 of the coachees were interviewed by phone where they described their experiences from the coaching program. Interviews were recorded, transcribed, and analyzed by inductive qualitative content analysis. This kind of analysis was chosen as there, as far as we know, are no previous studies dealing with this kind of parental coaching in T1D and therefore there was no theory to try (23). In order to increase trustworthiness, the analysis was carried out by the project manager and the last author together. According to the content analysis, raw data were organized and analyzed by open coding, creating categories and abstraction to identify themes for the interviews.

### Phase 5. Confirmation

To increase the credibility and to give the participants an opportunity to confirm the results of the qualitative content analysis, they were invited to a second workshop. Coaches (n = 3), coachees (n = 7), adolescents (n = 2) and team members (n = 2) participated in this workshop. During the workshop, the results of the content analysis of the interviews were presented to the participants. In order to reach consensus agreement, they were asked if they agreed with the presented results or if there was anything they wanted to change or add. They were also given the opportunity to comment and come up with suggestions on how information and instructions for future coaches and coachees could be developed.

**Table 2.** Examples of Subcategories and the Four Touch Points From the Interviews and Focus Groups.

Touch points	Subcategories
Information and knowledge	Learn from the beginning from the diabetes team Both parents and child/youth get knowledge That friends get knowledge
To get understanding and support	To meet others in the same age with diabetes Learning to accept diabetes Motivation and self-esteem
To learn the technique	Learn how everything works (eg, insulin pumps and continuous glucose monitoring) To adjust insulin doses based on food/exercise
Focus on HbA1c	Feeling of failure HbA1c "could be a spur to try better" Big focus on numbers (eg, HbA1c) that can be misleading

### Ethics

The participants were informed that participation was voluntary and they could withdraw at any time without explanation. The study was approved by the Regional Ethical Review Board (Dnr: 2017/216-31).

### Results

During the interviews and the focus groups, the participants were committed and shared generously their experiences about what they considered needed when coping with everyday life with diabetes. It was agreed that it was important to gain knowledge and the right information from the beginning after diagnosis. Everyone around the child must have a deepened knowledge about T1D and how it is treated. They also described the importance of getting support in order to accept the disease. Both parents, children, and teams portrayed extensive focus being placed on HbA1c, and this sometimes took focus from other important aspects. They also described the importance of learning how to handle all technical equipment associated with diabetes treatment. The analysis of interviews and focus groups was summarized and resulted in 4 touch points, listed in Table 2.

During the workshop, improvement ideas were discussed based on the touch points. At the end of the meeting, the group agreed that coaching should be prioritized because it was possible to start rather quickly and it included several of the important issues described in the touch points.

During the 5-month test period, 15 coaches were recruited and 10 coach-couples were matched (Table 1). Diabetes nurses asked the experienced parents (note 2) if they wanted to be coaches. When a child was newly diagnosed with T1D,

**Table 3.** The Theme, Categories, and Subcategories From the Content Analysis of the Interviews.

Confidence and self-efficacy		
Subcategory (Coaches)	Categories	Subcategory (Coachees)
	⇐                      ⇒	
<p><b>To share knowledge and experience</b>                      “You (the staff) can answer a lot but you may not know how it is to live in this situation”</p> <p><b>To grow through insight about own knowledge</b>                      “When I think about it, I really know quite a lot about this. Instinctively you know what to do and what not to do”</p> <p><b>To be a sounding board</b>                      “She had a few questions she wanted to air”</p> <p><b>Networking</b>                      “I would recommend others to be coaches it creates a network of contacts”</p> <p><b>To brace and convey security</b>                      “As a coach, I want to give some hope, everyday life will work”</p> <p><b>Want to be a role model</b>                      “I hope we will be able to show that you can live with diabetes”</p>	<p><b>To contribute to and to gain competence</b></p> <p><b>To give and to get a feeling of hope</b></p>	<p><b>Take part in lived knowledge and experience</b>                      “A little more life experience, that’s what you need in this situation”</p> <p><b>Getting a network</b>                      “It’s good to know that there is someone else you can call, not just the hospital”</p> <p><b>Being able to ask stupid questions (outside the hospital)</b>                      “I really think you need people you can just pick up the phone and call, to ask quick, stupid questions that you maybe wouldn’t call the hospital for”</p> <p><b>Not to feel alone</b>                      “To feel that you are not alone in all of this and that you can get small pieces of advice on how other people have solved different problems. To see that it works and that you can actually live quite a normal life”</p> <p><b>To be braced for managing everyday life</b>                      “Then you can have a role model who can show you that you can do lots of things, for example that he can play hockey several days a week even if he has a pump”</p> <p><b>Feeling safe</b>                      “The coach has contributed to a little more security. And that he said that it is a lot at the beginning, it will calm down and it will be fine”                      “You feel safer hearing it from someone who has been through the same thing”</p>

the project manager asked the parents if they wanted contact with a coach. If so, the project manager called a coach whose child was about the same age or lived relatively close to the family. The coach was given the name and telephone number of the coachee and was asked to send a text message and then call him/her. The contact between the couples varied. Some of them had a lot of contact with each other while others had less contact. Some met each other while others only had telephone contact.

To evaluate the coaching program, interviews with the coaches and the coachees were performed. The analysis resulted in the main theme: “Confidence and self-efficacy,” based on the 2 generic categories “To contribute to and to gain competence” and “To give and to get a feeling of hope” (Table 3).

The coaches described that they had become aware of their own skills and that this competence was unique to them and added something that health-care staff could not give the parents:

“You (the staff) can answer a lot but you may not know how it is to live in this situation”

This insight about their ability seemed to strengthen them. The coachees described that they valued having access to this particular knowledge. Parents who had been in contact with a coach stated that they could get answers to questions that the health-care staff could not give them. They also felt stronger and safer:

“You feel safer hearing it from someone who has been through the same thing”

Both coaches and coachees expressed the need for a network and someone to share everyday issues with:

“It’s good to know that there is someone else you can call, not just the hospital”

Coaches expressed a joy in sharing their knowledge and experience and they also described that it felt admirable to give something back which they had experienced as a need when they were in the same situation:

“As a coach I want to give some hope, everyday life will work”

When the result of the content analysis was presented to participants at the workshop, they confirmed that the analysis of the interviews represented their views. During the workshop, there were discussions in mixed groups and suggestions were given on topics for coach couples to discuss and how contact with new coaches should be planned for in future coaching programs. For some of the coach couples, the workshop was the first time they met and they had a lot to talk about. One coach couple brought their children to the workshop so that they had the opportunity to meet. Participants agreed on that the coach project was so successful that it should be implemented in regular care. After the workshop, the diabetes team decided to implement the coach program at the department on a regular basis.

## Discussion

Previous improvement efforts made within the current team were based on what the health-care staff considered important. The fact that both the patients and staff have developed the improvement effort may have contributed to the fact that it is perceived as important and is accepted by all stakeholders. According to Kennedy et al, effective support for self-care requires “a whole systems perspective that engages patient, practitioner, and service organization” (25). We conclude that using EBCD provides an opportunity to engage all stakeholders involved.

Research on and treatment of diabetes often focus on HbA1c. This is understandable as HbA1c is linked both to quality of life (6,7) and risk for complications (3). However, it can be unfortunate to only focus on this measure as it may not be what the person with diabetes himself perceives to be most important. Likewise, other studies have found that there was a need and demand for support from others in the same situation. The coaches’ description of having the opportunity to give back what was missing when their children were diagnosed with diabetes is something also described in a Welsh study that largely resembles this coach-project (26). Sullivan-Bolyai and Lee interviewed parents with experience of diabetes who acted as mentors to parents whose children were recently diagnosed with diabetes. The results in this study are similar to our study; the parents talk about experiences of being aware of their own skills, being able to question everyday issues and sharing their experience (27). These similarities strengthen the trustworthiness and indicate that the result is not entirely dependent on the current context. It has been shown that parents’ beliefs about their ability to influence their child in “a health and success promoting manner” seems to be a key to healthy functioning in parents and children (28). There is some evidence that parental perceived diabetes self-efficacy is found to be an independent predictor of glycemic control (29,30). This makes it important to explore what can be helpful for children, adolescents, and parents to cope with everyday life with diabetes and to find ways to strengthen parents’ self-efficacy.

The overall theme “confidence and self-efficacy” show that coaching for parents of children with diabetes leads to an improvement in the parents’ self-rated measures, such as increased self-confidence and reduced disease stress, also reported elsewhere (31). Self-efficacy has been defined as “one’s confidence to take action to achieve a specific goal” (32). Marchante et al has shown that there is a correlation between high score on the Parental Self-Efficacy Scale for Diabetes Management and better glycemic control and quality of life in children (33). Chih et al has shown that high self-efficacy is related to good metabolic control in young people with type 1 diabetes (34). The subcategories “getting a network” and “not to feel alone” may highlight the sense of coherence that has been found to be important for parents of children with diabetes (35).

The connection between good metabolic control during the first 3 to 15 months with diabetes and the risk of complications later in life highlights the importance of a good start is well established (5). However, getting the opportunity to ponder everyday issues, thoughts, and feelings with someone who understands can then be a piece of the puzzle to better managing everyday life and thus also more easily achieve and maintain a good metabolic control is also of importance. Therefore, an evaluation of parents’ self-efficacy should be recommended in future research on parental coaching for children and adolescents with diabetes (36). It has been described that there is missing evidence about the effectiveness of interventions that focus on parents alone, or delivered only in hospital settings (37).

## Methodological Considerations

Experienced-Based Co-Design as a method supports the knowledge that the people involved are an important resource in the development of improvement ideas. The coach program has limitations as it excludes people who do not speak Swedish. One limitation is that the number of school staff invited is unknown which could have affected the result. Another limitation is that focus groups with adolescents was replaced with one-to-one interviews, consequently the possibility of interaction between the participants was not possible (38). To strengthen the analysis, two of the authors performed the analysis. Another limitation is that the coaches got no education or instructions about the coaching. The validation phase represented a kind of member check, which also strengthen the results (39). One limitation due to the study design is the deficiency regarding transferability, as the study was only performed in the context of supporting parents to children with T1D and in one site. However the results of our study have been confirmed from other studies (26,27), which must be seen as a strength.

## Conclusions

Experienced-Based Co-design was an effective way to develop improvement suggestions within the current

diabetes team. The method gave an opportunity for identification of improvement idea that was supported by all stakeholders. Utilizing the lived experience of parents through a coaching program may be an effective way to increase self-efficacy for both the coaches and the coachees. We would like to recommend parental coaching, as a way to support parents' also in chronic diseases other than T1D.

### Authors' Note

All participants in our study have given their informed consent before taking part in the study. This is mandatory before conducting studies in Sweden. The participants were informed that participation was voluntary and they could withdraw at any time without explanation. The study was approved by the Regional Ethical Review Board (Dnr: 2017/216-31). The authors warrant that the article is original, does not infringe upon any copyright or other proprietary right of any third party, is not under consideration by any other journal, and has not been previously published.


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### Notes

1. Experienced parents are parents whose child has had diabetes for at least 1 year.
2. Experienced parents are parents whose child has had diabetes for at least 1 year.

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