



## Article

# “Sometimes You Just Need People around You Who Understand You”: A Qualitative Study of Everyday Life at a Residential Care Unit for Young People with Diabetes

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**Abstract:** Solglimt is the only long-term residential care facility in Denmark for young people with diabetes who, for various reasons, are particularly exposed or vulnerable. This target group is characterized by poorly regulated diabetes and psychosocial challenges. As this unique setting and specific target group has not been studied before, we designed a qualitative sociological study of the experiences and perceptions of everyday life from the perspectives of current and former residents as well as from those of the residential care social workers (RCSWs). We also studied the specific care practices at Solglimt. The dataset consists of nine days of participatory observations, 29 semi-structured individual interviews with three target groups (9 current residents, 8 former residents and 12 RCSWs) and three participatory workshops. All data were analyzed using radical hermeneutics. The analysis produced four main themes: (1) In it together, like a family—feeling different among peers, (2) Social workers as substitutes for parents and healthcare professionals, (3) Individualization—Increased self-confidence and autonomy, and (4) Tacit knowledge and illness behavior automation. The findings show that the residential care facility is a family-like setting with a strong focus on individualization, which enables new illness behaviors and perceptions. The results offer important steps towards developing improved diabetes care strategies through individualized informal knowledge sharing. Furthermore, the results are applicable to general clinical diabetes care for vulnerable or low-resource children and young people with diabetes.

**Keywords:** diabetes; residential care; young people; social workers; qualitative research; psychosocial effects; illness behavior



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## 1. Introduction

Type 1 diabetes is one of the most common chronic illnesses among young people. Effective therapies are available but require adherence to a daily treatment regimen that requires constant self-management. This includes balancing insulin dosing, carbohydrate counting, and physical activity, along with frequent feedback from blood glucose monitoring results. However, nonadherence and suboptimal glycemic control are significant concerns for adolescents. While self-management constraints can be difficult to adhere to at all ages, glycemic control is the poorest during adolescence. Many adolescents do not regain satisfactory glycemic control until they reach 30 years of age (Miller et al. 2015; Clements et al. 2016; Foster et al. 2019). Furthermore, it is well-established that the patient education and care provided to young people with chronic somatic illnesses, including diabetes, are rather inattentive to the complex set of challenges related to the multitude of physiological, social and emotional changes that characterize the transition into young adulthood (Wood et al. 2018).

Young people with poorly regulated diabetes often experience recurrent hospitalization, behavioral problems, lower academic achievement and negatively affected school performance, higher incidence of psychiatric disorders and diagnoses, diabetes-specific

stress, and family dysfunction and conflicts (Delamater 2009; Vaid et al. 2017; Knychala et al. 2015; Cohen et al. 2004). Moreover, dealing with a psychiatric diagnosis influences living with diabetes as well as achieving satisfactory medical outcomes and psychological well-being (Young-Hyman et al. 2016). Given the plethora of short- and long-term health difficulties related to diabetes, it is crucial that young people with diabetes learn to manage their diabetes effectively (Lind et al. 2009).

Solglimt is a Danish long-term residential care unit for children and young people with diabetes, both type 1 and type 2. The diagnosis of diabetes is a prerequisite for living at Solglimt; however, to be granted a place, it is also required that residents be particularly exposed or vulnerable, and many of them have a psychiatric diagnosis. Therefore, the residents at Solglimt are severely at risk for the serious complications associated with diabetes. They are referred to Solglimt to reduce the negative influences from their original environment and to improve their glycemic control and psychosocial well-being. Daily care is provided by social workers under the close supervision of the local pediatric diabetes clinic.

Research has indicated that residential care can have unintended consequences, for instance, not sufficiently protecting children against violence, bullying and abuse, while also causing them to experience increased stigma and being viewed as ‘troublemakers’ (Dansey et al. 2019). Residential care for children and young people who cannot live with their families is an ambivalent institutional system that has continuously been viewed as a ‘positive choice,’ but at the same time as the ‘last resort’ (Mollidor and Berridge 2017). Further, young people living in residential care have often experienced challenging familial relationships and relationships that have not been a site of constant positive emotional and physical comfort (Archer and Gordon 2013; Emond 2014). Moreover, leaving residential care and having to adapt to new conditions can present yet another burden and additional risks for the children (Luksik and Hargasova 2018). Therefore, entering residential care and the time spent in residential care can expose young people with diabetes to further risk. Nevertheless, the research has also shown some of these children are able to prosper (Luksik and Hargasova 2018).

Everyday life at a residential diabetes care unit has never been studied. Therefore, the objectives of this paper are to conduct a sociological study of experiences and perceptions of everyday life in a residential care facility, from the perspectives of current and former residents as well as from those of the social care workers. We accomplish this by employing a complex dataset generated through participatory observations, semi-structured individual interviews with the three target groups, and participatory workshops with residents and social workers. The study was designed to pay specific attention to the particular kinds of challenges young people in residential diabetes care experience and how they cope with them. Working with the social education of residents with a serious chronic illness like diabetes—individuals who also have varying degrees of special needs for care in relation to psychosocial difficulties—is a significant challenge for the social workers at the residential care unit. A secondary objective of the study is therefore to investigate the specific care practices employed at Solglimt.

The present study is not only relevant to people working with young people in a residential diabetes care unit, as the results also provide valuable insights for researchers and clinicians working with vulnerable young people with diabetes in general.

## 2. Materials and Methods

An iterative, three-stage, exploratory qualitative design was used, including observations, in-depth semi-structured interviews and participatory workshops. This approach was chosen to gather in-depth data that allow an exploration of everyday interactions, lived experiences as well as perceptions.

All data was collected by L.B.J. (research assistant) and supervised by D.G. (senior researcher), both of whom work at a specialized diabetes management research facility. The analysis was done by both authors.

### 2.1. Observations

The initial phase of the present study commenced with participatory observations of the residential care home. In total, nine days of participant observations were carried out by the first author. The observations were primarily used to build up trust and contextualize the subsequent interviews (DeWalt and DeWalt 2011).

The aim of the participant observation was to understand explicit and tacit aspects of the residents' and RCSWs' (residential care social workers) everyday routines in the institutional setting. Therefore, we decided that, in order to acquire a clear understanding of the routines, contexts, environment, and role of each person involved in the situation, including their thoughts, feelings, and actions, we needed to be part of the situation and involved in the activities in the actual study setting (DeWalt and DeWalt 2011; Kristiansen and Krogstrup 2015). Furthermore, as this setting has never been systematically investigated before, participant observation enabled us to gain insider perspectives, allowing this knowledge to influence and inform the subsequent interviews as well as the overall findings (Bonner and Tolhurst 2002).

Jot notes on all of the events observed on observation days were taken on the observer's mobile phone; these were later expanded on and written out more fully (DeWalt and DeWalt 2011).

### 2.2. Recruitment

The target groups for this exploratory study were current residents, former residents and residential care social workers (RCSWs). The RCSWs informed the 11 residents who lived at Solglimt at the time of the interviews and their parents about the study. RCSWs and current residents were recruited during the observation days. Former residents were recruited by one of the authors (L.B.J.) at an annual event for former residents. At the time of recruitment, 11 adolescents lived at Solglimt and 21 former residents participated in the annual event.

In all, seven girls and four boys lived at Solglimt at the time of this study. Of the 11 residents, 9 residents (6 girls and 3 boys) with a mean age of 17 years (range 15 to 20) agreed to be interviewed. The mean length of their stay in Solglimt at the time of the interviews was two years, ranging from three months to four years. The average time since diagnosis with diabetes was eight years, ranging from one year to 17 years.

We interviewed eight former residents with a mean age of 26 years (range 19 to 32). The average length of time residing at Solglimt was three years (range 1 to 6). The average length of time since leaving Solglimt was eight years (range 2 months to 15 years). We decided not to interview former residents if more than 15 years had passed since they lived at Solglimt.

All of the RCSWs were interviewed (7 women and 5 men). Their length of employment at Solglimt ranged from four months to 20 years. Half of them had been working at Solglimt for 10 years or more.

### 2.3. Interviews

In total, 29 in-depth, face-to-face, individual semi-structured interviews were conducted (8 former residents, 9 residents and 12 RCSWs). All interviews were recorded and transcribed verbatim. The interviews lasted between 23 and 152 min. The average time for the interviews was 52 min (avg. residents: 36 min; avg. former residents: 39 min; avg. RCSWs: 81 min). The interviews were semi-structured. A range of open-ended questions were posed covering the following themes: (1) Institutional everyday life: with questions focusing on the individual and collective everyday life at Solglimt, (2) Diagnosis and self-understanding: with questions focusing on the individual experience of having diabetes and other diagnoses in and outside the institutional context, (3) Social workers' practice: with questions focusing on the role of the RCSWs' actions and relationships, and (4) Residents' practice: with questions focusing on the positioning and relationships among

the residents. All specific interview-guides were focused on the individual experiences of living/working at the residential diabetes care facility as well as on the personal narratives.

All interviews were facilitated by the first author. The first interview with each target group was considered a pilot-test and therefore evaluated and discussed by the researchers. No changes were made in the interview-guides and all interviews were therefore included. The interviews with current residents and RCSWs were conducted whenever they could be fitted into the daily schedules at Solglimt. The interviews with former residents were conducted in their homes or in a nearby café. The interviews with RCSWs were planned and conducted from their work schedules.

All interviews were conducted individually, as this was likely more comfortable for them, giving them room to express more personal thoughts and experiences (Punch 2002).

#### 2.4. Workshops

Based on observations and interviews, three participatory workshops with six to 12 participants (4–8 current residents and 2–4 RCSWs) were conducted. The workshop method was chosen to create a dynamic and in-depth understanding of the initial results, as well as to promote transparency and involvement on the part of the participants (Ørngreen and Levinsen 2017).

The participatory approach employed in the design of the workshops originates from health promotion research where participation is regarded as perhaps the most central of all health promotion principles, in the sense that sustainable change can only take place if the target groups have the opportunity to develop ownership—and ownership and internalization are more likely to be achieved if the target groups are actively involved in the processes (Grabowski et al. 2017).

The workshops lasted two hours and took place at Solglimt. All three workshops were organized in three sessions containing different dialogue exercises and included group discussions as well as individual reflection. The workshops consisted of both joint sessions and split sessions, where participants were divided into smaller groups or with the residents and RCSWs separately.

The workshops were facilitated by the first author and focused on topics revealed in the interviews and observations related to institutional everyday life. The themes for all workshops were chosen on the basis of what was most relevant for the residents. Dialogue tools were designed to prompt conversations between residents and RCSWs and facilitate sharing of positive and negative experiences. The dialogue tools were designed specifically for the Solglimt study based on prior experience with participatory dialogue exercises and more specifically on dialogue tools from the Family Toolbox (Grabowski et al. 2019). For example, using one of the dialogue tools, participants individually built a fictional typical resident before, during and after their stay at Solglimt with statements and quotes (for example: ‘targeted’ and ‘alone with diabetes’); the figure dealt with emotions, knowledge, support and expectations and was discussed afterwards.

The third and last workshop included a joint session in which the initial results from the interview study were presented and thereafter discussed by the participants. This was intended to support a process of validating the research findings and making them reliable and relatable through participatory meaning negotiation (Ørngreen and Levinsen 2017).

The two initial workshops were digitally audio-recorded and transcribed verbatim. In the third workshop, we decided to just take notes—thus creating a more confidential space, as the themes for this workshop could be particularly personal and intimate for the residents.

#### 2.5. Data Analysis

After collecting each dataset, the recordings of the interviews and workshops were transcribed verbatim and transferred to NVivo software, where they were iteratively analyzed in Danish and then categorized by both authors using radical hermeneutics. The expanded jot notes were analyzed manually.

Radical hermeneutics is a set of guidelines for content analysis that, as a combination of hermeneutics and constructivism, manages to simultaneously be empirically grounded and theoretically complex (Rasmussen 2004). Radical hermeneutics focuses on keeping a perpetual balance between theory, method and data by acknowledging how all of these elements influence each other in an interconnected process. The use of radical hermeneutics also entails constant alternation between analyzing and interpreting, which means it is necessary to present interpretive aspects while presenting the results.

Radical hermeneutics is a validated methodology consisting of three steps of data analysis. The first step involves reading the data with a view to observing specifically selected differences in them. This observation in itself constitutes an interpretation rather than a description, and its task is to reduce the complexity of the data. Elements within the scope of the differences selected by the interpreter are extracted from the data. The second step involves making these elements the subject of interpretation as an observation of the differences employed. The third step involves interpreting the sum of these differences (ibid.).

In the present analysis, this approach meant that the analytical process was developed in several steps as we delved deeper into the data. The first step focused on extracting from the empirical data issues of direct relevance to the institutional everyday life, diagnosis and self-understanding, social workers' practice and residents' practice. In this phase L.B.J. and D.G. conducted the coding independently and discussed the identification of themes. The second step involved analyzing and interpreting the extracted data, and this step revealed the four main themes presented in the Results section. Theme developments were discussed and agreed on. The final step is then a separate interpretation of the data within each category, materializing as the findings presented for each of the four themes.

## 2.6. Ethics

The study was approved by the Danish Data Protection Agency (P-2019-199) and carried out in accordance with the Declaration of Helsinki. According to Danish legislation, interview and observation studies require no approval from an ethics committee. All participants gave their informed consent based on a thorough explanation of the purpose of the study. All participants were told that they had the right to abstain from answering any question and that they could stop the interview at any time if they were uncomfortable with the situation. Furthermore, they were given details of whom to contact for answers to questions about the research and the rights of research subjects.

## 3. Results

The complexities of being a young person with diabetes living at a residential care home and the ensuing challenges of being a social worker working within these complexities are presented in the four themes below. The themes are strongly interconnected and, in some cases, even interdependent.

### 3.1. *In It Together, Like a Family—Feeling Different among Peers*

Most of the young people described living at Solglimt as being a part of a small isolated community—one that differs radically from other young people's communities, as it consists entirely of peers with diabetes and a variety of difficulties and care needs. Further, because it is full-time, it becomes a unit that demands socialization, not unlike a family or sibling relationship. As one of the residents put it:

“You become really close in a place like this . . . I mean, I spend more time with people here than I do with my own siblings! And we see them every day and we say goodnight to each other . . . So we're like a small family—at least among us young . . . We have all the same, you know, relations . . . and we have the same problems.” (Current resident #5)

Even though this resident mentioned positive relationships within the residential care unit, she also described an ambivalent relation between the consequence of having been

forced to sever ties with her family and her social networks and living at the residential care unit with peers who have similar challenges who have become some of her closest friends. This ambivalence was described by many of the current and former residents.

The closeness in the residential care unit was, however, also made up of other social positions, a sort of social hierarchy, where one has to know one's place. This required struggle, negotiations, acquisition of specific competences and understandings of unspoken rules of the resident group, as was described by a former resident as follows:

"Of course we had a lot of girl-conflicts, 'cause we were only three girls here . . . So we had to form the girl-group 'cause otherwise it would always be two against one . . . but before that some of the guys had to back me up 'cause I was all alone . . . but then again, I was the new girl and therefore the weakest link."  
(Former resident #3)

The most dominant finding, however, was the positive experience of living with peers who also have difficulties managing their diabetes. For most of the residents, diabetes had previously been a burden and an intrusion that disrupted their hopes of being like everyone else. Being around peers gave the residents a feeling of normality and of no longer being alone. Two residents described it in this way:

"Here, I'm fine with it (glucose testing), but that's 'cause we've all got diabetes which makes it a bit different. And that's really the reason why I'm so happy that I'm here now. I'm not alone with things anymore. People understand you here."  
(Current resident #3)

and

" . . . and sometimes you just need people around you who understand you—and people understand you here, 'cause they're in the exact same situation as you are. It has really helped a lot that it's that big thing we have in common."  
(Current resident #2)

Present and former residents all reported that living with other people who understand the difficulties of having diabetes helped them in their diabetes management and in many psychosocial aspects of having diabetes. During the observation study, some residents mentioned that when they (before Solglimt) had met peers with diabetes, they had seen them as 'perfect diabetics' whom they could not relate to. Living with peers who were experiencing the same difficulties gave them a feeling of no longer being socially isolated:

"Well, when I lived at home I was absent a lot from school, so I lost contact with friends from school. In the end I had no friends left . . . But now it's different."  
(Current resident #5)

Even though the residents described the relations in the residential care unit as family-like and predominantly beneficial, they also described how they felt very different from each other:

"Right now, there's a very diverse group of people living here—with friendships forming across groups and very different lives. It's really cool."  
(Current resident #6)

The residents further described that the friendships established at the residential care unit would probably not have been established in any other contexts. Some residents described it this way:

"You really get to know people and it's people that you would never hang out with back home. But you kind of have to 'cause you live together. I like it. I like living here with all these people."  
(Current resident—workshop)

Through observations and interviews with the residents, it became clear that the relationships established at the residential care unit could have a positive influence on residents' self-understanding, as most of the residents reported having become more tolerant, understanding and caring during the time they lived at Solglimt. The residential

care unit functions as a space where they have to navigate between their past relationships and enter into new relationships. This space is responsible for building up the routines, rhythms and rituals of residential care, as well as the relational and emotional aspects of their everyday life.

### 3.2. Social Workers as Substitutes for Parents and Healthcare Professionals

At Solglimt, many of the residents used family-related terms to describe the RCSWs. These were predominantly used when describing the relationship with their primary RCSW. This relationship was described by many of the residents as trustworthy and caring, but also as annoying and strict. One current resident and one former resident described it as follows:

“Well, Vinnie and I, we’re just like mom and daughter, really. She wants to tell me what to do and I don’t want her to tell me what to do . . . Sometimes we argue and sometimes we go out and eat lunch together. It’s up and down, really . . . It’s fine. She’s OK . . . When I need help, she’s really there for me.” (Current resident #3)

and

“We tried our best to work our way towards each other. Sometimes we would argue just like you would back home with your mom and dad . . . But I loved it. It was what made me feel safe.” (Former resident #6)

These descriptions are consistent with the observational data. There were constant negotiations between the residents and RCSWs about aspects of restrictive control. The described feeling of family-like relationships may be reinforced by many of the ‘parenting’ roles and tasks that the RCSWs, especially the residents’ primary person, fulfill: for example, taking residents to the hospital, having contact with school and waking them up in the morning.

All RCSWs described the importance of maintaining a family-like environment instead of an institutional one and, thereby, also creating a caring and parental relationship with the residents. One RCSW put it this way, when explaining the importance of the relationship:

“When we go on institutional trips, it’s really great. We don’t do it for the salary, ‘cause that really sucks. We do it because it’s great to be away for 5–7 days, because we see the kids in a different way and they see us in a different way. When we get back home, you can actually feel that the relationship is stronger.” (RCSW #5)

This RCSW was referring to different national and international trips the residents and RCSWs go on together, organized by Solglimt. The RCSWs further argued that being aware of relational dynamics plays a significant role in how they do their job, as the line between professional and personal resident-RCSW relationships often gets blurry, due to the work-related responsibilities and reciprocal sharing of personal stories.

Building close relationships with each individual resident helped establish the RCSWs’ knowledge about each resident’s diabetes, which then added to the residents’ feeling of being heard and understood. One resident reflected on the weekly diabetes conversations with their primary RCSW:

“Birgitte knows everything about my diabetes, so it’s her that I need to have these talks with. She knows everything about everything.” (Current resident—workshop)

All residents mentioned being frustrated about healthcare professionals (from the time before Solglimt) not understanding their individual needs. Among other things, several of them had experienced receiving a great deal of information, guidelines and restrictions from healthcare professionals and then just being sent home, where they would systematically ignore all of it—often resulting in them also ignoring their diabetes and their

self-management. The residents emphasized the importance of being understood as an individual with individual needs and challenges:

“I used to think that all doctors and nurses were complete idiots, ‘cause I just felt that they would never understand me ‘cause they’d never had diabetes, right? And then I came here where they have these social workers who’ve worked with it for ages and where there’s all these other kids who can give you little pieces of advice about what really works and what doesn’t.” (Former resident #1)

This former resident further described how the frustrations related to not being understood by anyone had given her a feeling of being alone and ‘abnormal.’

Many residents talked about how the RCSWs created a safe space for ‘testing’ how different aspects of their daily diabetes management affected their diabetes. This helped them come to understand their diabetes in a way they never had before. One of the former residents described it as follows:

“And I remember that my primary contact once said to me: ‘ok, now we’ll see what eating this cake does to your blood sugar’ and then we tried it. Stuff like that really helped and we created that bit of learning together.” (Former resident #5)

The residents often described their stay at Solglint as a process of acquiring the tools needed to manage diabetes without the overwhelming number of restrictions they were used to. The close relationships at Solglint played a significant role in this process.

### 3.3. Individualization—Increased Self-Confidence and Autonomy

In most interviews with the RCSWs and in the observational data, it is significant that the pedagogical approach employed at Solglint is largely characterized by individualization. The RCSWs emphasized the importance of individualization, given the many differences among the young people and their various problems and challenges:

“All our young people come here with their own kind of mental challenges and then they have diabetes on top of that—that’s the reason they’re here. So we need to have many ways to approach that.” (RCSW #10)

There was significant variation in the goals and priorities set for the residents at Solglint. Overall, the RCSWs described their role as a ‘guidance counselor’—overseeing diabetes management, school performance, well-being and everyday life. The role as ‘guidance counselor’ is most explicit during the weekly conversation about diabetes, in which they guide the residents in setting individual goals for what to improve or maintain.

“We have these weekly diabetes talks where I have this one girl who really wants to make her own decisions. And of course that makes sense ‘cause she’s the one who has to live it and do it. So I give her some of the responsibility and say: ‘OK, we’ll try that.’ They have to be the main part of the journey, so it has to make sense to them.” (RCSW #1)

It is important for the RCSWs to communicate to the residents that they are responsible for their own life and for the direction and speed of progress. The residents seem to value this responsibility balance, as it helps them understand and accept the nature of the required progress:

“It all helps. But you can’t help yourself until you pull yourself together—and I haven’t really reached that point yet.” (Current resident #3)

This girl further explained that she was still struggling with accepting having diabetes, as she experienced several other factors in her life that complicated her diabetes self-management.

Many residents explained that they found it difficult to accept having diabetes and, as a consequence, also found it hard to talk about their diabetes. One of the RCSWs explained how she tried to keep the weekly diabetes conversation unstructured and on the resident’s terms:

“He’s not the type where you can just go ‘hey Simon, I need to talk to you now.’ He’ll maybe come home and then I’ll ask ‘what plans do you have?’ and he’ll say ‘none, really’ and then I’ll ask him if we can maybe talk in an hour . . . And it’ll always be informal and on his terms.” (RCSW #6)

The individualization pursued at Solglimt had given residents a feeling of having ‘special rules’ and more self-confidence; they felt the RCSWs trusted them. This was explained by one of the residents:

“The social workers tell me that I’m allowed to do more things than some of the others. But that’s ‘cause they know they can trust me . . . And that’s cool, but I know that it comes with the expectation that I do the things I need to do.” (Current resident #6)

Furthermore, some of the residents explained that they experienced their degree of progress in comparison with one another and that the ensuing reflection had altered their self-understanding.

“Well, take me for example. I’m changing by being together with all of these people. They’re almost adults, all of them and they make me feel like I have to give more of myself and take myself more seriously.” (Current resident—workshop)

All residents saw themselves as gradually becoming more mature, and they had all experienced improvements in their self-confidence. This was often expressed through stories of improved school performance, experiences of making adult choices and decisions, and improvements in their family relationships.

The young people reported feeling more confident in the institutional setting, which also affected their opportunities for performing inside and outside Solglimt. Before moving to Solglimt, they had often experienced low self-esteem caused by their diabetes, which they described as greatly affecting their school performance, friendships and family relationships. All residents mentioned that living at Solglimt had helped them see themselves as more independent:

“Well, I’m not that little insecure girl anymore. Now I dare to stand up for myself and say ‘I don’t want to be a part of this.’ I wouldn’t have done that before.” (Current resident #4)

### 3.4. *Tacit Knowledge and Illness Behavior Automation*

All residents stated that they had acquired more knowledge about diabetes at Solglimt. When asked to specify exactly what they had learned, it was difficult for them to pinpoint, but they talked about everyday tools that were embodied through practices in formal and informal institutional contexts. One of the former residents reflected on the knowledge she had acquired at Solglimt:

“It was here at Solglimt that I learned that when I’m high (blood glucose), then I pee a lot and drink a lot and that it makes me tired and lazy. At the hospital, they would just show you a picture or something but at Solglimt, they would really explain it in a way that would really make sense.” (Former resident #6)

The residents described how the daily routines and rituals in the institutional peer-group setting had provided a form of automation that allowed them to change their illness behavior without actively basing it on knowledge and without thinking about it every time. The setting furthermore created a space in which the residents influenced each other in terms of behavior and acquired knowledge. This was described by two of the residents as follows:

“We help each other . . . So, if one of us is checking his blood sugar then the rest of us will also do it . . . So it’s something that just happens automatically.” (Current resident #4)

and

“I kind of think that diabetes plays a big role in everything here . . . But you don’t really think about it . . . I mean, you have to constantly check your blood sugar or take insulin and stuff like that—but it’s just that we’re so used to doing it that we don’t think about it.” (Current resident #3)

This kind of automation of diabetes management was mostly described as happening in the institutional setting and in other contexts together with peers from Solglimt. Hence, the institutional setting was perceived as a normalizing factor in relation to the otherwise irregular experiences of controlling diabetes. Consistent with this, the observational data revealed tacit conventions in the diabetes practice played out at Solglimt, especially among the residents. This also emerged in the interviews with RCSWs. One of the RCSWs reflected on the residents’ interaction:

“And then when they come here they always go: ‘Oh it’s really nice that you feel the same way! Does your toe hurt too? Could it be because we have diabetes?’ They have a lot of issues and emotions in connection with diabetes that they can share.” (RCSW #2)

In contrast to the institutional setting, many of the residents described the individual non-institutional settings as a ‘time off’ where they just wanted to forget everything about diabetes:

“When I’m away from here I feel like it’s a holiday . . . So I kind of stay as far away from diabetes as I can.” (Current resident #7)

Most residents at Solglimt reported being really happy about not having to think so much about diabetes and about achieving some automation in diabetes-related tasks. The theme of not wanting diabetes to be a significant part of everyday life came up in most interviews as well as in the workshops. In one of the workshops, one resident reflected on what he hoped for when leaving Solglimt and having to manage diabetes on his own:

“Well, that’s where I want to be! It (diabetes) will never be a friend, but to just feel that it’s there but you don’t notice it . . . That it’s not such a major thing.” (Current resident—workshop)

There was some ambivalence in the residents’ desire to not let diabetes play a significant role in their everyday life, through automation of diabetes-related tasks. A large part of this automation was due to institutional rules and structures, but the young people complained about these rules and were constantly asking for more freedom. As one former resident put it:

“Well, when I left Solglimt it all went wrong for me. All of a sudden there was no structure and no rules and I could do whatever I wanted. So I ended up going out partying every Thursday, Friday and Saturday.” (Former resident #4)

This former resident, like many of the other former residents, reported that during the period just after leaving Solglimt, he still had difficulties managing diabetes. Nevertheless, the knowledge he gained at Solglimt was meaningful and is important to him now—several years after having left Solglimt:

“It means that I’m better equipped to live with the disease I have. I have some tools now. There was this one social worker there who also had diabetes and he said ‘You need to control the diabetes. It must not be the diabetes that controls you.’ Tools like that to make you reflect.” (Former resident #4)

This description is consistent with what many of the other former residents said and reflects that the knowledge acquired, especially the ‘everyday tools,’ did not only concern diabetes management, but also managing everyday life in general.

#### 4. Theoretical Perspectives

As this is a novel area of research and because we wanted to keep the study as open as possible, we did not apply specific theories to our data analysis. There are, however, several theoretical directions that could be explored when interpreting our current findings

and applied to future studies. Some of the most striking findings concern the significant contextual differences between the residents' life before Solglimt and after arriving at Solglimt—as well as the ensuing process of making sense of this new setting, while at the same time trying to establish oneself within the setting. This could be analyzed and interpreted using Luhmann's systems theory (Luhmann 1995), which would enable us to look more closely at the meaning-making structures that dominate the systems these young people are trying to navigate within. It is significant that the individual resident's observation of communicative structures plays a central role in the acquisition of knowledge about diabetes, about being a young person in general and, perhaps most importantly, about how to meaningfully observe and relate to communication coming from people with authority. Conducting a theory-based study of communicative structures at a residential diabetes care unit would generate important knowledge about how we can successfully communicate diabetes information to vulnerable young people in general.

Another option would be to carry out a study focused on the identity development that is very clearly taking place among these young people, who are negotiating self-understandings in a new and very different setting. With our current findings in mind, such a study could use Waterman's theories of delineated self-definitions (Waterman 1984) and Marcia's definition of identity, where identity is a sense of having continuity with the past, an active direction in the present, and a future trajectory (Marcia 2014). These theories would enable a focus on the most important aspects of how residents do identity work at Solglimt.

## 5. Discussion

Institutional life at a residential care unit for young people with diabetes has never been researched before. Our study has provided important and novel insights into residents' and RCSWs' experiences and perceptions of institutional everyday life at Solglimt. It also adds important knowledge to the broader research field of vulnerable young people with diabetes.

As no one has ever done research with this unique target group in this very unique setting, our findings are not directly comparable to anything in the research literature. Our findings do, however, reflect and support previously published findings in studies of vulnerable adolescents with diabetes as well as studies of adolescents in residential care homes. Specifically, our results support Mollidor and Berridge's (2017) findings on the ambivalent experiences of children and adolescents in residential care. On the one hand, the residents in our study described Solglimt as a 'positive choice,' in that they experienced family-like, positive, supportive and caring relationships in a setting where they achieved a degree of automation of illness behavior due to the informal knowledge they gained. On the other hand, they also described Solglimt as the 'last resort,' because they had been forced to leave their family and friends as they were unable to manage diabetes on their own. This ambivalence seems to be predominantly driven by their desire to pursue a 'normal' teenage life.

In contrast to Dansey et al. (2019), who found unintended consequences of being placed at a residential care home, our study indicates that the residents experienced less bullying and stigma related to their diabetes after being placed at Solglimt. Living among peers who have diabetes was described as being understood and not being alone anymore. All residents could relate to each other even though they felt very different from each other. This indicates that living in residential care with a group of people dealing with the same disease somehow changes some of the dynamics otherwise found among children in care homes. This finding needs to be researched further.

As indicated in our results, the residents' learning about diabetes included both tacit and explicit forms of knowledge. We can classify this knowledge into four settings: individual, peer-group, institutional and non-institutional. The combination of institutional norms, interpersonal negotiations, and tacit and explicit knowledge had resulted in each resident's knowledge set for making decisions during their stay and, during the years after

leaving Solglimt, was very much individualized on several levels. This knowledge included how to manage diabetes and everyday life in general through firsthand experience over time. Tacit knowledge was an important element at Solglimt, as many of the residents had previously discarded information from healthcare professionals due to bad experiences.

One main finding of our study was that the residents found many of their self-management tasks challenging, particularly in individual non-institutional contexts. A common way of dealing with this challenge was to ignore these tasks, as they did not want to prioritize them when they were 'finally at home.' Hence, many former residents experienced a deterioration of their illness behavior when they left Solglimt. Similar findings were reported by [Luksik and Hargasova \(2018\)](#), who stated that leaving residential care can present a burden and additional risks for the children, and that only some of these children are able to prosper. It is imperative to find ways to address this issue, especially in light of these vulnerable adolescents' elevated risk of developing serious long-term diabetes-related complications ([Lind et al. 2009](#)).

Our study also highlights the significance of individualization and building relationships in the effective treatment of this target group. The findings underline the importance of the RCSWs' role as guidance counselors with a blurred line between personal and professional relations as they, simultaneously, worked as substitute for parents as well as healthcare professionals. The role of the RCSWs enabled them to pay attention to the complex set of challenges during the transition to adulthood ([Wood et al. 2018](#)). This was described as positive by the residents, as they felt a different understanding/empathy for the struggle of being a young person with diabetes.

Regarding methodology, the use of mixed qualitative and participatory methods constitutes a strength of the present study. One of the main strengths of our study is the unique setting of Solglimt. We had access to all aspects of daily institutional life and were met with very positive attitudes towards being interviewed and participating in workshops. This meant that we had the best possible prerequisites for conducting a unique and in-depth study of a small, closed setting.

The same small setting also created some natural limitations for the study. As it was only possible to interview nine currently residing children, the sample of current residents is relatively small. However, the inclusion of former residents as well as the additional data we obtained from the workshops more than compensated for this limitation.

The present findings provide a promising direction in the pursuit of effective treatment for this high-risk and under-researched target group of vulnerable young people with diabetes. This study is the first to demonstrate that a multidisciplinary residential care treatment approach provides significant psychosocial benefits for this population. The next step of this research will be to use our current findings to develop, implement and test specific guidelines for how RCSWs and healthcare professionals can support diabetes management and quality of life among young people with diabetes.

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