

In a vigilant state of chronic disruption: How parents with a young child with type 1 diabetes negotiate events and moments of uncertainty

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Abstract

Living as a parent and self-care surrogate of a young child with type 1 diabetes (T1D) is demanding and a disruption to ‘normal’ routinized daily living. Research has mainly focused on the time of diagnosis as a one-time biographical disruption. In this article, we will show how, in the case of families with young children with T1D, the biographical disruption can be viewed as a continuous state of vigilance that affects family functioning and ‘normal’ living. We will show this by focusing on the temporal events and moments that keep the families in a state of what we will term ‘chronic disruption.’ The events are the transitions from hospitalization to home, home to nursery, nursery to daycare, and daycare to school and preparations for social activities concerning the child. The moments are more fluid, ranging from daily interruptions when daycare workers and teachers call parents with doubts about self-care to negotiations with institutions and municipalities and a constant state of worry.

Keywords

Diabetes, family, everyday life, online offline ethnography, disruption

Introduction

The prevalence of diabetes continues to rise globally. Type 1 Diabetes mellitus (T1D) is one of the most common chronic diseases in childhood, and research estimates that the incidence is increasing (Patterson *et al.* 2009). Although T1D onset generally has been associated with early adolescence,

recently there has been a rapid increase among young children of preschool age (Bruno *et al.* 2016). Worldwide, the number of children under 14 years of age with T1D was estimated to be 497,000 in 2013, with more than a quarter living in Europe (Patterson *et al.* 2014). Despite this rising incidence, limited research has been done on how having a young child with T1D affects the family on a daily basis.

T1D is a chronic autoimmune illness with a very demanding self-management regime. Continuous support for daily self-care for T1D is crucial; 95% of care is done entirely by patients and families outside clinical practice settings (Funnell and Anderson 2004). In general, self-care and management for T1D are portrayed as challenging, because they require development of knowledge, skills, bodily and technological know-how, as well as learning practices such as injecting insulin, changing vials and needles, and navigating digitalized devices such as insulin pumps and continuous glucose monitors (Hernandez 1996, Mol and Law 2004, Guell 2012, Danholt 2013).

While several studies have been conducted on adults with T1D with a focus on self-care, management and coping, the literature on families with a young child with T1D remains limited. There are several reasons why the surrogate role of responding to a child's blood glucose level is considered demanding. Self-care for the child requires insight and sensibility regarding how the internal state of the body is influenced by external factors related to food and lifestyle, something a young child is unable to communicate, predict and respond to appropriately (Kingod 2017). Other factors concern the fact that a young child with T1D cannot conduct self-care and management without the support of an adult, as the treatment regime is complex, involving administration of insulin, monitoring of blood glucose, and restrictions in diet and physical activity. The study on parent's information and support need's when a child is diagnosed with type 1 diabetes by Rankin *et al.* (2014) elucidates how parents feel overwhelmed by healthcare professionals' instructions and advices. Their findings stress how parent's need more practical and emotional support after the diagnose.

A child diagnosed with a chronic illness causes a disruption not only to the child, but to the whole family, causing identities and normality to be renegotiated. Although research is lacking on families with young children with T1D, compelling work on families with children with other chronic illnesses can be found in the social science literature. Bluebond-Langner's (1996) *In the shadow of illness: Parents and siblings of the chronically ill child* portrays families with children with cystic fibrosis and how they both adjust their idea of a normal life and cope with the uncertainty of a biographical disruption. In relation to uncertainty in the wake of illness, there is a long history of studies

accentuating family or parental coping as a psychological resource and showing how contextual discrepancies influence coping strategies (Norberg *et al.* 2005).

Bury (1982), one of the first to describe chronic illness as a biographical disruption, builds on Giddens's concept of 'critical situation' by looking at the routinized day-to-day situations that are disturbed by illness. Bury demonstrated how people with rheumatoid arthritis experience both a bodily and relational disruption. Thus, the biographical disruption that Bury and others discuss is based on the single shocking event of receiving a diagnosis – a shock that with time disappears when living with a chronic condition becomes the new normal. Using her concept 'vital conjuncture,' Jennifer Johnson-Hanks argues for a new anthropology of the life course, while stressing that vital life events are rarely coherent, clear in direction or fixed in outcome. Instead we should look at the combination of events. Johnson-Hanks has been inspired by Bourdieu's conception of the conjuncture of structure and action. When criticizing the popular life-stage assumption that is widely used interdisciplinary, she focuses on the notion that institutions and aspirations are multiple and changeable, having several temporal frames. This correlates with Caroline Bledsoe's (2002) concept of 'contingent life course,' which is based on research on a birth interval project in Gambia. Through her analysis, she states that: "*Senescence is not linear. Rather, the hardships of life inscribe themselves on the body at a pace that is contingent on external events*" (p. 322). In her argument that life is not linear, she proposes a 'contingency' argument while criticizing the Western approach of measuring human reproductive capacity.

Studies in the area of youth research have focused on events, critical moments and transitional turning points connected to going through and overcoming chronic illness, however often paying attention to singularities such as leaving home, starting a family and transitioning from school to work (Thomson *et al.* 2002). Many of these studies have been inspired by Giddens's (1991) definition of a 'project of self,' which includes experiences of 'fateful moments' defined as times when events come together that are surrounded by risks and choices. Although disruption and uncertainty as concepts are applicable to the intrusion of various chronic conditions in a family system, it is important to investigate both the nature of the chronic illness and its required treatment regimen, the age of the child at diagnosis, and the contextual system wherein daily management is played out.

In the present article, we propose a concept of chronic disruptions as a specific state of vigilance that parents are constantly in, from the time of diagnosis and through the many daily negotiations of

uncertainty experienced in the surrogate self-care role. We explore this by examining the daily challenges and problem areas faced by Danish parents of young children with T1D, paying attention to both disruptive stable events and fluid moments of uncertainty as well as how parents manage these chronic disruptions by maintaining a constant attentive state.

Research setting: contextualizing Danish families with young children with T1D

About 32,000 people are living with T1D in Denmark, which accounts for an estimated 10% of the overall diabetes population (both type 1 and type 2) (Jørgensen *et al.* 2016). Of this total, there are about 3,800 children with T1D in Denmark, of whom 700 are below 8 years of age.

When young children are diagnosed, this is done using a glycated hemoglobin (A1C) test that indicates the average blood glucose level for the past three months. An A1C level above 6.5 percent on two separate tests indicates T1D. Signs and symptoms of T1D usually develop quickly over a period of weeks and include increased thirst and urination, extreme hunger, weight loss, fatigue, irritability, fruity-smelling breath, blurred vision, and/or yeast infection. In Denmark, during hospitalization, all children with T1D are taken care of by multidisciplinary teams, consisting of pediatric diabetologists, diabetes nurses, dieticians, and pediatric psychologists. After the first week of hospitalization, children and families are seen in the outpatient clinics at least three to four times a year (Olsen *et al.* 2014).

Parents must acquire knowledge about how to manage the child's disease and control his/her blood glucose level regularly. Limited diabetes education and support have a negative effect on the child's blood glucose level, which can lead to severe complications and mortality (Bruno *et al.* 2016). A child with T1D needs lifelong treatment and support from adults, because treatment includes administration of insulin either through an insulin pump or purpose designed pen, monitoring of blood glucose, and diet restrictions. Thus, diabetes has a major impact on the life of a child, as well as the family or caregivers, and studies have shown that parents found T1D to be an extremely difficult diagnosis that causes significant family disruption (Whittemore *et al.* 2012).

Insulin pump treatment is usually offered to people who experience poor glycemic control or children with T1D, as studies have shown that insulin pump use supports stricter blood glucose control and prevents or reduces episodes of hypoglycemia (Pickup and Keen 2002). Thus, handling an insulin pump requires the ability to read, calculate and problem-solve at a high level. Therefore, daily self-

care tasks are primarily imposed on parents and caregivers in daycare institutions. While parents always play an important role in T1D management, the child's role in T1D management depends on the child's age, cognitive development and understanding of self-management tasks (Sargent and Baker 1983, Anderton *et al.* 1989).

Denmark is a small country of six million people living in five regions and 98 municipalities. The tax funds are used to pay for the different expenses that Danish society has such as welfare benefits, state pension, child benefits and for public institutions such as schools, hospitals, and the police. It is the municipalities that deliver social services to people with chronic illness, such as support hours for the child when at nursery (0-1 years of age), daycare (3 years of age) and school (5-6 years of age). Whereas treatment tools for the child are paid for by the regional hospitals, support tools are paid for by the municipalities. Upon diagnosis, the parents must apply to the municipality for necessary support hours and reimbursement for additional expenditures and lost earnings, and often they must educate social workers on the demanding task of caring for a child with T1D. Support hours granted varies from municipality to municipality.

Methods

A qualitative study combining offline and online data was carried out to thoroughly describe the phenomenon of the challenges and obstacles faced by parents of young children with T1D. To do this, we employed a phenomenological approach (Kvale and Brinkman 2009, Bernet *et al.* 1993). Phenomenology as a method obtain descriptions of parts of people's lifeworld experience (Husserl 1928). In the following, we describe how we carried out a triangulation of qualitative methods.

Data collection consisted of three phases. First, three focus group discussions were carried out with nine families with children (from 3-6 years old and diagnosed from 6 months to 4 years old) with T1D. Second, we conducted an online study of a closed, secret Facebook community and, third, we conducted three in-depth telephone interviews. This process involving three phases was based on our initial findings, highlighting three areas for further studies. As such, the whole process was guided by findings and continually adjusted.

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The research team began the fieldwork offline with the three focus group discussions, which were held at a Danish outpatient diabetes unit; a diabetes endocrinologist and two diabetes nurses managed the recruitment process. The objective of the focus groups was to understand the familial experience of T1D at the time of diagnosis as well as the at-home self-care work of the child, with a particular focus on times of uncertainty in the caregiver role. Recruitment turned out to be challenging, as parents of young children with T1D are a vulnerable group with a high level of distress. Some parents cancelled on the day of the discussion due to lack of time and emotional resources. The parents in the focus groups reported being active members of Danish online peer-to-peer communities on the social media platform Facebook.

We therefore chose a combination of offline and online methods. The second data collection process occurred within a Facebook community for parents of children with T1D. It can be described as a closed community consisting of 680 members. Facebook has three levels of community building: Open communities, closed communities and secret communities. Creating closed Facebook communities is the most common method of establishing an online community focused on a chronic illness. Secret groups (often smaller than the larger closed communities) require invitation by administrators, as they cannot be searched for. Since launching its community pages function in 2010, Facebook is increasingly used as a space for individuals to establish health-related peer-to-peer groups that turn into larger interactive communities (Kingod 2018). The first author was allowed access to the larger and general community for parents of children with T1D and to a smaller secret Facebook group consisting of 8 mothers of preschool age children with T1D (one of the mothers in the focus group discussions worked as a gatekeeper and allowed us access to this group). Observations were conducted non-obtrusively so as not to interfere with the natural environment (Nørskov and Rask 2011). Notes were taken on interactions within the text-based posts, just as one would carry out observations in offline fields to capture any signs of uncertainty in the caregiver role; particular attention was paid to events and moments. Facebook's built-in functions were used, such as typing into the search field keywords from thematic/patterned findings based on analysis of the focus groups. Searches included the following keywords: 'diagnosis,' 'insertion', 'severe hypoglycemia,' 'hyperglycemia,' 'municipalities,' 'financial support,' 'nursery,' 'daycare' and 'school'. The many observations carried out online were used as background information in the analysis.

In recent literature on online ethnography and data gathering, there has been a debate about whether online data are sufficient in their own right or should be combined with offline data, such as interviews, focus groups and participant observations (Hine 2015). In the third and final data collection phase, telephone interviews were carried out with mothers from the secret community to obtain in-depth knowledge about the immersive caretaking role. We were interested in gaining in-depth insight into the phenomenology of caregiving as well as the contextualization of the described problem areas. Spradley (1979) stressed the importance of detailed context descriptions that pay attention to places, events, actions and activities to fully understand a given phenomenon, which we further unfolded with the interviews.

Focus group moderation and individual interviews were structured to allow uncertainty in daily life to be disclosed, and in this way the many disruptions of daily life became evident. We were inspired by Seidman (2006), who suggested giving space to open-ended questions in the first part of the focus groups using a general, loose framework, the goal being to reveal everyday life experiences with T1D. After the initial open-ended questions, we guided the focus groups and probed answers to overall themes and questions, moving toward uncertainty and disruptions. When gathering background information from Facebook, we conducted keyword searches of areas disclosed in the initial offline data.

In the analysis process, we looked for disagreements, levels of involvement, reactions to certain expressions, communality of experiences, and thematic consensus (Wibeck *et al.* 2007). In the second stage of data analysis, while going back and forth between patterns and categories, we paid attention to the stages, events and moments of disruption and uncertainty in relation to the caregiver role. We worked in a reductionistic manner to thematize parents' conscious experience of illness-related negotiations in daily life (Husserl 2017). Through the thematization process, we have developed a working definition of 'chronic disruptions' as a descriptive concept to further analyze the families' biographical accounts and their relationship with social structure. Particularly through analysis, we revealed chronic disruptions to be events and moments the families attended to that were delineated as having important consequences for family function, quality of life and wellbeing, for the family, the parents as well as the child with T1D.

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The focus group discussions were video-recorded and translated verbatim for later analysis in the software program NVivo. Informed consent, privacy, and confidentiality are basic ethical tenets of research involving people. The informants were informed about the possibility of contacting the clinic for professional emotional support if needed.

We scheduled half an hour of free peer-to-peer talk in the middle of the discussion, which allowed informants to share their contact information with each other. The informants expressed gratitude for the opportunity to meet with like-minded people with similar problems and challenges.

Written consent was received from all informants in the study and we have removed personal and sensitive information from any quotes. When carrying out research on potentially sensitive issues in small communities, there is a risk of unintentionally disclosing the identity of informants if using direct quotes. The information from Facebook was used as background data without revealing sensitive and personalized information. Just one quote has been used directly from a secret unsearchable group with written consent from the informant. We have followed the seven considerations for researchers before, during, and after data gathering offline and online proposed by Eysenbach and Till (2001). The considerations are intrusiveness, perceived privacy, vulnerability, potential harm, informed consent, confidentiality, and intellectual property rights. The project design and research approach have undergone evaluation and been approved by the Danish Data Protection Agency (SDS-2017-024 05932).

Results

Onset – the revelation

The diagnosis was the first important disruptive event for all parents where they had to acquire new and complicated knowledge to be able to secure the health and wellbeing of the child.

The analysis reveals that parents felt overwhelmed by grief and anxiety upon diagnosis, which made it challenging to take in information during the week of hospitalization in relation to their new caregiver role. They referred to being ‘bombarded with information’ by healthcare professionals, such as nurses, dieticians, and doctors, ranging from learning about the pathology of the disease to the many comprehensive care practices, such as blood glucose measurements, insulin injections,

changing vials of insulin, carbohydrate calculations, as well as understanding the child's individual blood glucose rhythm and how food and exercise will affect it. They particularly described their fear of doing something wrong that would harm the child. Handling the needles and attaching an insertion on the child for insulin injections were considered difficult.

I thought that I would never learn it (how to attach an insertion on the child). With shaky hands I practiced it on a teddy bear and even on an orange, and I would go to the bathroom several times and just cry (Mother of a 5-year-old daughter with T1D).

Although initially a daunting procedure, changing an insertion for insulin injection is something that must be carried out at least twice a week, and therefore it became a routinized practice. However, it was only routinized in the sense that the practice, at the micro-level, was carried out without taking into consideration the many (un)likely moments when the insertion simply falls off, making the practice even more frequent. This could happen when the child was playing on the playground, and the cord to the insulin pump got stuck, which would tear out the insertion, cutting off the flow of insulin. In this situation, one of the parents must change it. According to the families, it was always difficult to change the insertion, as it caused the child some pain. However, these moments were often ritualized to be a 'cozy moment,' when the child could watch a cartoon and have a small treat like a piece of candy, thus reframing a negative experience into a more pleasant and positive one.

Whereas some parents found the week of hospitalization stressful, other parents said it was even worse when they left the hospital and had to put all the information they had received at the hospital into practice on their own.

I felt so much stress and I just didn't want to change the insertion. I just couldn't! And we had to go to the hospital for support, but then the nurses convinced me that I had to learn it. It was very barrier-breaking to do that on your own child (Mother of 3-year-old boy with T1D).

The first period after hospitalization there is a hotline to call at the diabetes unit, however many families found this type of support insufficient, because uncertainty in self-care of T1D is likely to arise many times a day. The type of support families need is more experience-based and tailored knowledge that other families with similar experiences can best offer, through peer communities on

the social media platform Facebook. Families talked about fear and distress, especially regarding how to stabilize blood glucose levels outside the normal range.

And then we came home after 6 days at the hospital and we were so afraid. I was happy about the 24-hour hotline and I used it a lot in the beginning. I had no clue. What if I give her an ice-cream, will I kill her? I just didn't know in the beginning (Mother of 4-year-old girl with T1D).

Controlling blood glucose level involves taking into consideration how food and exercise affect it, allowing one to predict their effects. These prediction practices have a constant impact on the caregiver role, leading to excessive controlling of the child's blood glucose level out of fear that a miscalculation might end in severe hypoglycemia, with risk of unconsciousness and coma. Although a high blood glucose over time might lead to long-term complications, families and caregivers mostly reported fearing the risk of severe hypoglycemia. Families described posting about their fear in peer-to-peer support communities on Facebook. Uploaded posts were concerned with incidences of experienced severe hypoglycemia, which, although rare, were often referred to as a 'parent's worst nightmare.'

Struggling with access to support hours and recognition

Although the Danish welfare state does supply support for families with chronically ill children, to access these support services require help from engaged social workers at the municipality to document the complicated caregiver role and the risks for families without enough supporting hours.

Families described time-consuming practices of seeking support hours for the child and reimbursement for loss of earnings. Some municipalities have limited previous experience with young children with T1D, and therefore parents must educate not only daycare workers and school teachers, but also municipal social workers. This finding accords with interactions on Facebook, where parents compared granted financial support for the child – comparisons that revealed vast differences across municipalities. The families with fewer support hours found it difficult to balance the uncertainty of daily life with the illness, and mothers were often periodically absent from work so that they could function as a hotline. Mothers could even take over care for the child at the institution entirely when care for the child was not performed properly.

There was a great difference in the number of granted support hours across municipalities, and families revealed a range of 0 to 37 support hours a week. The families with limited granted hours felt more anxious about handing over responsibility for care to daycare workers and school teachers in an already strained system with large class sizes. This is reflected in a quote:

We have big problems getting extra hours from the municipality. It's a real fight. You spend a lot of time on municipal matters; whether it's about hours for extra support or additional costs. It can take the breath away from someone with a surplus of mental resources. Everywhere we encounter people who have no understanding of type 1 diabetes and the huge responsibility for care involved. It's hard. (Father of 3-year-old boy with T1D).

The quote shows that it was not only support hours for the child that were at issue, but also additional costs such as rubbing alcohol for blood glucose measurements, juice and dextrose, insulin pump belt bags for the child, and special medical lotions for eczema and rashes, which are unwanted side effects of devices that are attached to the body to monitor blood glucose. Funds for these additional costs were typically applied for once a year, and if granted give a fixed monthly reimbursement. This is a necessary task in addition to the intensive self-care regime.

During an individual interview, the mother of a 6-year-old girl with T1D described her fight with her new municipality about receiving enough support hours for daycare. Due to the limited number of hours, the daycare workers were having difficulties caring for the child, resulting in cases of both hypoglycemia and hyperglycemia during a week in the daycare. She informed us that she was struggling to maintain her employment, as the daycare workers often called her when they were uncertain about how to perform the caregiver role. Fear for her daughter's safety had forced her to take sick leave several times, given the many daily disruptions when she must speak with uncertain daycare workers and the emotional burden of the potential risk her child was being exposed to. This was why she had asked her employer for more work-at-home days, which allowed her to be close to the daycare in potential life-threatening situations.

First, we were granted 10 hours, but that was not enough. He (the child) is in a very large institution, and the environment is often chaotic. Then the leader of the institution discovered there were not enough hours to conduct proper self-care for my child. Then we got 20 and now we are down to 15. You must fight for hours every year. And when there

is a change in staff, and I need to be there to train the new one. And there has been a lot of turnover (Mother of 4-year-old boy with T1D).

The families did not only face lack of understanding at municipal level about the great self-care regime necessary for controlling the child's blood glucose level. Some families also reported that schools had rejected the child with T1D due to their uncertainty about caregiver procedures. On these occasions, the families had turned to the Danish Diabetes Association for guidance and support on legal aspects and the correct use of legal paragraphs to put a pressure on the school board.

Uncertainty about caregiver roles and responsibilities and the vulnerability to any shortcomings in the daily team around the child were problems families often discussed with each other in the focus groups as well as on Facebook.

Passing on the caregiver role

Whereas in the weeks after hospitalization parents could use the hotline, they also served as a hotline themselves – for daycare workers and teachers when uncertainties arose concerning how to respond to fluctuating blood glucose levels. Families discussed the difficulties of passing on knowledge about self-care when they were still very insecure and engaged in learning it themselves.

When you leave the hospital, you must train daycare workers, who are very scared. And when you're scared it's difficult to listen. We were also beginners and therefore our training was not structured, and when we became more routinized, we had to change our explanations. There are so many changes around this disease and especially with the digitalized technology for monitoring the blood glucose level. We had to change our treatment protocol several times and that was not only hard for us, but also for people in our surroundings (Mother to 4-year-old girl with T1D).

The hospital offers two hours general training targeting institutions; however, parents regarded this information as too general to be truly supportive. Although it is free of charge, not all institutions can find the time to participate. With just a few, or no, support hours, there are few resources for educating daycare workers and teachers.

We were extremely challenged in the nursery. I had three months sick leave, but we used almost two months in the wardrobe of the nursery to measure the blood glucose and give insulin. The leader could not find time to educate the daycare workers and said that we should consider the daycare a place where she could ‘just come and play, nothing more’. Then they were tired of us hanging around and said that we should learn to let go. When my husband for the first time was away for a few hours he came back to a child that had an extreme low blood glucose level (crying). What if he had been away for 15 more minutes! They were afraid to give her food because of her diabetes (Mother of a 5-year-old girl with T1D).

Particularly the mothers received many calls every day, related to how to count carbohydrates, how to raise or lower blood glucose levels, and how to navigate the insulin pump. At times there were malfunctions with the technology, and then one of the parents had to leave work to pick up the child. This could be a situation where the cord that attaches the insulin pump to the body has fallen off or the continuous glucose monitor also attached to the body and connected to the insulin pump had lost its signal. Posts on ‘insertions’ on Facebook mainly related to when it suddenly falls off during playtime and activities and parents have to leave work.

I prepared a lot of documents. Everything they had to do and schedules for all the carbohydrates. Almost like a diabetes book for dummies. Then I thought that it would be easy for them when they had to measure her blood glucose. And then they called me all the time and I had to count carbohydrates for them over the phone to be able to adjust the insulin pump. It was very difficult to manage work. I was called about 20 times a day. I always have my phone on me. I get very stressed if I forget it somewhere. They must be able to contact me. What if it’s something serious! (Mother of a 4-year-old child with T1D).

The smartphone has become a necessary lifeline between the institutions and the parents. Smartphones were always carried around close to the body, allowing mothers to respond to emergency calls from daycare workers or teachers. The mothers described how the phone’s ring tone always makes them anxious that something bad has happened to the child. Mothers would panic if phone batteries were low or if they were unable to immediately respond to calls. This is something the mothers in the secret Facebook group would joke about, however with a serious undertone. A mother from the secret group described how the school secretary called and left a message on her phone stating that they had a ‘critical and acute situation.’ The mother immediately called back, because she thought her child had severe hypoglycemia. When she talked to the school

secretary, she informed her that one of her teachers had called in sick. Fear of hyperglycemia was one of the most debated topics in the closed Facebook community and secret group as well as in the focus groups.

The Danish Diabetes Association states that about 50 people around a T1D child should be knowledgeable about the disease and be able to provide emergency aid for the child (The Diabetes Association). This was not the case for the informants, and the observations on Facebook revealed a more limited support network, often with fewer than five people trained to provide self-care for the child. Parents revealed the difficulties of finding people in their network to educate as supportive caregivers, because understanding how to control fluctuating blood glucose levels is not only something that can be taught by reading manuals, it also needs to be practiced continuously in relation to the individual child's daily rhythm.

We only have a grandmother. But he can't sleep over at her place. It is just too much to ask of her because she would have to set her alarm clock all the time. And what if she didn't hear the pump alarm. That would just be terrible. I don't know if I would be able to let go. But it's a big help that she can pick him up every Wednesday. (Mother of a 5-year-old boy with T1D).

In the above quote, the mother referred to the nightly procedure of measuring the blood glucose level several times. In the focus group discussions, the parents talked about how they would take shifts at night, as the many disruptions in sleep patterns were exhausting and effected parents throughout the day. With a limited caregiver network, parents needed to shadow the child, following him/her to events and activities such as sports and hobbies, playdates, birthday parties and the like to keep the blood glucose level within the normal range and avoid a potential life-threatening situation.

There are so many birthdays where I always have to sit in the corner. She is so tired of it and often says 'mother when are you leaving! Why don't you just leave like the other parents,' and I say to her 'sweetheart, mommy will hide in the corner.' But I cannot hide. I always have to follow her, when she's this young. I am always the extra wheel and she never gets any rest from me.

On Facebook, parents often posted their concerns about sport and exercise, how to avoid low blood glucose levels, and how they had to be extra cautious, observant and attentive to the child in these circumstances. There were also discussions around when you can let go of control of the child in relation to playdates, and whether it would be responsible to educate the child's friends' parents.

Discussion

In the literature, biographical disruption has often been described as the time of diagnosis when people or relatives with chronic illness and disability negotiate a new identity. Bluebond-Langner (2000) considers how, in the year following their child's diagnosis with cystic fibrosis, families are 'overwhelmed' by their new caregiver role. While questioning how parents manage and deal with their new role as caregiver of the child, she draws out fundamental issues of uncertainty and the strategies they employ to routinize and normalize daily life. She describes that it very much is a process of trial and error, where parents try to work the caregiver task into everyday life, concluding that over time even interruptions become routinized (Bluebond-Langner 2000: 138). Although her analysis shows that integration of caregiving tasks becomes routinized, normalized and ordinary after approximately a year, including less attention to uncertainty and interruptions, this supposition is not in accordance with our findings on parents of young children with T1D. Although a categorization of ordinary and extraordinary events in the daily life of families with chronically ill children can be defined as relative, we wish to argue that providing self-care for a child with T1D involves a state of constant vigilance from the time of diagnosis, when parents are negotiating uncertainty in their surrogate caregiver role. From the moment of diagnosis, the parents must learn, and very quickly, about how to work as a self-care surrogate for the child. There is no time to rest, grieve, digest and reorient oneself, because controlling and managing the child's blood glucose is a 24/7 task. T1D affects children's life in many situations and settings – from mealtimes, play, and sleep to daycare, school and making friends (Smaldone and Ritholz 2011). A study among older children describes how managing their diabetes can be painful and unpleasant and how they feel frustrated with the many daily disruptions caused by blood glucose measurements, insulin injections, and restrictions on certain foods (Rankin *et al.* 2017). A Swedish study concluded that mothers of children with T1D found self-management of the child extremely difficult due to constant control of the blood glucose and their great responsibility for the child's health (Lindstöm *et al.* 2017). Our study indicates that, within a family system, the surrogate caregiver role affects mothers in particular as they have to learn how to 'sense' the child's blood glucose fluctuation and

how to read important signs of danger that the child is too young to express (Kingod and Cleal 2019). No matter how experienced parents with a T1D child become in their caregiver role, the vigilance is still there in the back of their minds, because learning how to manage T1D is a chronic life-long process.

The anthropologist Lewis (1999) argues that daily life is a diffuse category that can only be considered in relation to special events. Through their accounts of the extraordinary challenges, we can start to understand their everyday life. By highlighting events as things that stand out from the daily life background, they can immediately be considered extraordinary in relation to ordinary or normal and routinized daily living. The many extraordinary events and moments that parents have to deal with have also sharpened their attention to blood glucose fluctuations the child is too young to express and communicate (Kingod 2018). At the systemic level, this is a vigilant state concerning how to navigate the Danish system so as to receive crucial financial support. By chronic disruptions, we are referring to a state in which parents are constantly vigilant both towards the child's health and surroundings and how to navigate the system for necessary support. Although events and moments are changeable and often also very unpredictable, the vigilant condition becomes 'normal'.

T1D is not a disease children are born with. It develops, still for unknown reasons, at different ages (in our study the time of diagnosis varied from 1 to 5 years), and therefore the families described the extraordinary disruptive events and moments in comparison to what they considered to be their normal life before the diagnosis. With reference to Lewis, the events and moments we have focused on in our analysis only become disruptive because of the levels of uncertainty in the caregiver role and the many obligatory management tasks that make it difficult for parents to maintain their 'normal' daily life.

The disruptive nature of the T1D diagnosis and the intensive self-care regimen was evident in our analysis and is in accordance with findings from earlier studies on how the complexity of the caregiver role affects family functioning. A clinical study showed how parents suffer from post-traumatic stress syndrome (PTSD) up to four years after diagnosis, and this confirms other studies showing how psychosocial distress or 'pediatric parenting stress' affects parents' years after the child's diagnosis, with challenges in coping with self-management tasks (Whittemore *et al.* 2012, Streisand *et al.* 2001, Streisand *et al.* 2005, Jaser *et al.* 2009). However, these studies did not investigate the disruptive events and moments families experience in relation to handing over

caregiver responsibilities or particularly the many negotiations with institutions they must have in their unceasing efforts to balance daily life.

T1D is a chronic illness that requires considerable knowledge to properly manage and control fluctuating blood glucose levels. This is not only a matter of insulin injection, but also often of predicting how exercise and food will affect the blood glucose as well as planning for and foreseeing events and moments. Whereas parents can plan to some extent for the events defined as developmental stages in the child's institutional life and routinized activities, such as sport, hobbies, birthdays, and playdates, the moments are more fluid, unpredictable and continuous. An example could be a malfunction in the many digital devices such as glucometers, insulin pumps and continuous glucose monitors or when the blood glucose, often for unknown reasons, rises or drops to unhealthy levels. Common to both events and moments is that they tend to continue and are difficult to predict and routinize.

Inspired by the literature and our empirical material, we have developed an analytical concept of 'chronic disruptions,' defined as events and moments when parents negotiate uncertainty and normalcy in their dual role as both caregiver and parent. We argue that these disruptive events and moments keep parents in a chronic vigilant state in their caregiver role in relation to the child. This is with reference to Giddens' (1991) statement about instances when 'critical moments and events' have important consequences for people's lives and identities. Parents have to learn that this chronic vigilant state is the new normal.

Based on our analysis, we define events as transitions from home to nursery, nursery to daycare and daycare to school. These are events that all children and families, despite chronicity, go through, thus, these transitions require considerably more preparation, time off from work and emotional capacity on the part of parents with a child with T1D. These transitions are disruptive in that parents are absent from work, and they must also apply to the municipality for reimbursement for loss of earnings so they will have enough time to educate daycare workers and school teachers. Although these events can be planned for, the analysis reveals great differences across municipalities in the number of support hours granted. With limited support hours, the interruptions become constant, as lack of training of daycare workers and teachers results in uncertainty in the caregiver role. Lack of support hours often means few caregivers, often just one or two, and increased vulnerability to family functioning due to any absence or calling in sick. This is illustrated when parents must take over the caregiver role at institutions when daycare workers or teachers are sick, or when they are

called several times a day with questions about how to control fluctuating blood glucose levels in various situations of daily life. As the analysis reveals, families often have a poor caregiver network to rely on, such as family members or friends who can be supportive in times of need.

The many uncertain situations surrounding the practices of selfcare were described as ‘stressful,’ because parents had to learn to perform self-care for the child, just as they had to manage their disrupted identity with continued illness-associated identity work in the normalizing process of adapting to the new situation and caregiver identity (Kingod et al., 2017). Johnson-Hanks’ (2000) concept of ‘vital conjuncture’ describes the disruptive nature of the often unpredictable combination of events among people with chronic illness. In our study, this was the case with disruptive everyday moments that were difficult to predict and act upon suitably. The unpredictability of disruptive moments was discussed by Bledsoe (2002) in her study in Gambia using the contingency argument. In times of hardship such as chronic illness, life is even more filled with unpredictable moments that must be negotiated. The negotiations involved in having a young child with T1D were in many cases based on fear of hypoglycemia when handing over responsibility for care to daycare workers. In a study by Herbert et al. (2015), fear of insulin shock was prevalent among parents when their children with T1D were at school. In Beck’s (1992) study, risks and outcomes for families with illness were entirely shaped by the social and cultural resources they had at hand.

The methodology of our study was limited to focus group discussions with families with young children with T1D and individual interviews with mothers, combined with keyword searches in a larger closed Facebook community and a smaller secret community. To capture the nature of how caregiver tasks are affected by social and material resources, life transitions and societal and institutional responses, as mentioned by Atkin *et al.* (2001), we could have included more stakeholders in our analysis, such as interviews with daycare workers and school teachers, as well as ethnographic field observations of daily caregiving interactions and negotiations at institutions.

Conclusion

Using empirical examples, we have tried to grasp the range of negotiations between parents of children with T1D and societal institutions as well as the many disruptive events and moments families are negotiating in daily life. These negotiations are based on the complexities of disease control and uncertainties in the new caregiver role of the child. We argue that parents of young children with T1D find themselves in a special state of chronic vigilance in their effort to function

as a self-care surrogate for the child, and to navigate the system to receive enough support hours for the child and educate nursery, daycare and school to eliminate risk and danger. The topic of complexities of self-caring has been raised within different fields with attention to people of all ages – young, chronically ill or elderly -, however with little attention to the role of relatives to patients. Caregiver roles comes in many formats where disruptions to normal living can be momentary, acute or chronic. Our notion of the parental role as a self-care surrogate for the child brings attention to a highly demanding state of vigilance in order to secure the health of the child. Our concept of a vigilant state of disruption can be explored across other chronic diseases where the caregiver role of sick children is challenging. While it is important to understand children's experiences, it remains important to understand parent's challenges, particularly in their roles as carers. More studies are needed to understand the vigilant state of parents to chronically ill children and how disruptive events and moments manifest among various contexts and disease groups.

T1D may be understood as being particularly vulnerable to the decisions and choices of others as they are responsible for self-care and monitoring of their illness. This is not to say that this dependency is not needed or positive, but when not attended to in the proper manner it can affect the child's quality of life. Future studies could address this great responsibility for care by paying attention to control and uncertainty, and especially how these aspects affect the child.

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References

- Anderton, J. M., Elfer, H., & Lai. (1989) Ideology in the clinical context: Chronic illness, ethnicity and the discourse on normalization, *Sociology of Health and Illness*, 11, 3, 253-278.
- Atkin, K., & Ahmad, W.I.U. (2001) Living a "normal" life: Young people coping with thalassemia major or sickle cell disorder, *Social Science & Medicine*, 53, 615-626.
- Bernet, R., I. Kern, and E. Marbach. (1993) *An Introduction to Husserlian Phenomenology*. Evanston, IL: Northwestern University Press.
- Bluebond-Langner, M. (1996) *In the shadow of illness: Parents and siblings of the chronically ill child*. Princeton, NJ: Princeton University Press.
- Bury, M. (1982) Chronic illness as biographical disruption, *Sociology of Health and Illness*, 4, 2, 167-182.
- Bledsoe, C. H. (2002) *Contingent Lives: Fertility, Time and Aging in West Africa*. University of Chicago Press. 2002
- Bruno, G., Gruden, G., & Songini, M. (2016) Incidence of type 1 diabetes in age groups above 15 years: facts, hypothesis and prospects for future epidemiologic research, *Acta Diabetol*, 53, 3, 339-47.
- Danholt, P. (2013) "Factish Relations: Affective Bodies in Diabetes Treatment," *Health (London)*, 17(4), 375-390.
- Eysenbach, G. and J.E., Till. (2001) Ethical issues in qualitative research on internet communities, *BMJ*, 323, 1103-5.

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- Funnell, M. M., and Anderson, R.M. (2004) "Empowerment and Self-Management of Diabetes," *Clinical Diabetes*, 22, 3, 123-127.
- Giddens, A. (1991) *Modernity and Self-Identity: Self and society in the late modern age*. Stanford University Press. Stanford.
- Guell, C. (2012) Self-care at the margins: Meals and meters in migrant's diabetes tactics, *Medical Anthropology Quarterly*, 26, 4.
- Herbert, L.J., Clary, L., Owen, V., Monaghan, M., Alvarez, V., & Streisand, R. 2015. Relations among school/daycare functioning, fear of hypoglycaemia and quality of life in parents of young children with type 1 diabetes, *J Clin Nursing*, 24, 9/10, 1199-209. Doi: 10.1111/jocn.12658
- Hernandez, C. (1996) Integration: The Experience of Living with Insulin Dependent (Type 1) Diabetes Mellitus, *Canadian Journal of Nursing Research*, 28, 4, 37-56.
- Johnson-Hanks, J. (2002) On the Limits of Life Stages in Ethnography: Toward a Theory of Vital Conjunctions, *American Anthropologist*, 104, 3, 865-880.
- Jaser, S.S., Whittemore, R., Ambrosino, J.M., Lindemann, E., & Grey, M. (2009) Coping and psychosocial adjustment in mothers of young children with type 1 diabetes, *Children's Health Care*, 38, 2, 91-106.
- Jørgensen, M.E., J.K. Kristensen, G.R. Husted, C. Cerqueira, C. & P. Rossing. (2016) The Danish adult diabetes registry, *Clinical Epidemiology*, 8, 429-434
- Kingod, N., B. Cleal, A. Wahlberg, and G. Husted. (2017) Online peer-to-peer communities in the daily lives of people with chronic illness: A qualitative systematic review, *Qualitative Health Research*, 27, 1, 89-99.
- Kingod, N. (2017) *The Tinkering M-Patient: An (auto-)praxiographic study of attuning to a life with type 1 diabetes through online and offline support*. PhD thesis at the University of Copenhagen. ISBN 978-87-7209-133-4
- Kingod, N. (2018) The Tinkering M-Patient: Co-constructing Knowledge on how to Live with Type 1 Diabetes through Facebook Searching and Sharing and Offline Tinkering with Self-care. *Health: (London)*, 24, 2, 152-168. Doi: 10.1177/1363459318800140
- Kingod, N. and Cleal, B. (2019) Noise as disappearance: Attuning to a life with type 1 diabetes, *Body & Society*, 25, 4, 55-75. doi: 10.1177/1357034X19861671.
- Kvale, S. and Brinkman, B. (2009) *Interview: Introduktion til et håndværk*. Hans Reitzels Forlag.

This paper has been accepted for publication in *Sociology of Health & Illness*, and the final (edited, revised and typeset) version of this paper will be published in *Sociology of Health & Illness*, Volume 42, by Wiley Online, All rights reserved. © Wiley

- Lewis, L.M. (1999) *Arguments with ethnography: comparative approaches to history, politics, & religion*. Berg Publishers, London, UK.
- Lindström C, Åman J, Norberg AL, Forssberg M, and Anderzén-Carlsson, A. (2017) "Mission Impossible"; the Mothering of a Child With Type 1 Diabetes - From the Perspective of Mothers Experiencing Burnout, *J Pediatr Nurs*, 36, 149-156. doi: 10.1016/j.pedn.2017.06.002.
- Mol, A., and Law, J. (2004) "Embodied Action, Enacted Bodies. The Example of Hypoglycaemia," *Body & Society*, 10, 2/3, 43-62.
- Norberg, A.L, Lindblad, F. & Boman, K.K. (2005) Coping strategies in parents of children with cancer, *Social Science and Medicine*, 60, 5, 965-75.
- Olsen, B, Johannesen, J., Fredheim, & S., Svensson, J. (2014) Insulin pump treatment: increasing prevalence, and predictors for better metabolic outcome in Danish children and adolescents with type 1 diabetes, *Pediatric Diabetes*, 16, 256–262
- Patterson, C.C, Dahlquist, G.G, Gyürüs, E, Green, A, and Soltész, G. (2009) Incidence trends for childhood type 1 diabetes in Europe during 1989-2003 and predicted new cases 2005-20: a multicenter prospective registration study, *Lancet*, 373, 2027-2033.
- Patterson C, Guariguata L, Dahlquist G, Soltész G, Ogle G, Silink M. (2014) Diabetes in the young - a global view and worldwide estimates of numbers of children with type 1 diabetes, *Diabetes Res Clin Pract*, 103, 2, 161-75. doi:10.1016/j.diabres.2013.11.005.
- Piazza-Waggoner, C., Modi, A.C., Powers, S.W., Williams, L.B., Dolan, L.M., and Patton, S.R. (2008) Observational assessment of family functioning in families with children who have type 1 diabetes mellitus, *J Developmental and Behavioral Pediatrics*, 29, 101-105.
- Pickup, J. and H. Keen. (2002) Continuous Subcutaneous Insulin Infusion at 25 Years: Evidence base for the expanding use of insulin pump therapy in type 1 diabetes, *Diabetes Care*, 25, 3, 593-698.
- Pierce J.S., Kozikowski, C, Lee, J.M., and Wysocki, T. (2017) Type 1 diabetes in very young children: a model of parent and child influences on management and outcomes, *Pediatric Diabetes*, 18, 1, 17-25. doi: 10.1111/pedi.12351.
- Rankin, D., Harden, J., Jepson, R., and Lawton, J. (2017) Children's experiences of managing Type 1 diabetes in everyday life: a thematic synthesis of qualitative studies, *Diabetes Medicine*, 34, 8, 1050-1060. doi: 10.1111.

- Rankin, D., Harden, J., Waugh, N., Noyes, K., Barnard, K.D., and Lawton, J. (2014) Parent's information and support needs when their child is diagnosed with type 1 diabetes: a qualitative study, *Health Expectations*, 19, 580-591.
- Seidman, I. (2006) *Interviewing as qualitative research: A guide for researchers in education and social science*. Teachers College Press.
- Sargent, J. and Baker, L. (1983) Behavior and diabetes care, *Primary Care*, 10, 583-594.
- Smaldone, A. and Ritholz, M.D. (2011) Perceptions of parenting children with type 1 diabetes diagnosed in early childhood, *J Pediatr Health Care*, 25: 87-95. doi:10.1016.
- Streisand, R., Braniecki, S., Tercyak, K.P. and Kazak, A.E. (2001) Childhood illness-related parenting stress: The pediatric inventory for parents, *Journal of Pediatric Psychology*, 26, 155-162.
- Streisand, R., Swift, E., Wickmark, T., Chen, B. and Holmes, C.S. (2005) Pediatric parenting stress among parents of children with type 1 diabetes: The role of self-efficacy, responsibility, and fear, *Journal of Pediatric Psychology*, 30, 6, 513-521.
- Thomson, R., Bell, R., Holland, J., McGrellis, S. and Sharpe, S. (2002) Critical moments: Choice, chance and opportunity in young people's narratives of transition, *Sociology*, 36, 2, 335-354.
- Wibeck, V., Dahlgren, M. A. and Öberg, G. (2007) Learning in focus groups: An analytical dimension for enhancing focus group research, *Qualitative Research*, 7, 2, 249-267.
- Whittemore, R, Jaser, S, Chao, A, Jang, M. and Grey, M. (2012) Psychological experience of parents of children with type 1 diabetes: A systematic mixed-studies review. *The Diabetes Educator*, 38, 562-579.