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Healthcare Professionals' Identification of, and Solutions to, Health Problems for *Hard to Reach* Patients with Diabetes

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Abstract

This article examines how healthcare professionals understand children with type 1 diabetes and their families, and how they consider them *hard to reach*. Based on observations and analysis of healthcare professionals' case conferences, the article finds that families' lack of compliance with professional recommendations is explained by parental lack of resources, ability, willingness, and complex social and personal problems of the family members. To find solutions to these diabetes management problems, the professionals integrate and synthesize knowledge based on experience, judgment, and practical skills. They also recognize organizational limitations of the healthcare system and, consequently, dependency on other organizations with other functions and knowledge. The article contributes to new knowledge about how organizations and professionals try to address and solve problems of health inequality in practice. A major finding is that the capacity to address individual health literacy depends just as much on organizational health literacy.

Keywords

Children with type 1 diabetes, health inequality, healthcare professions' practice and knowledge base, problem identifications and solutions

Introduction

Professions and their understanding of problems and solutions play an essential role in society's welfare organizations with crucial importance for society's ability to coordinate, integrate, and collaborate on solving societal challenges such as health inequalities.

International and Danish research shows that health inequalities among diabetes patients occur to a large extent (e.g. Borschuk & Everhart, 2015; Martin & Topholm, 2020; Walker et al., 2019). Research identifies a convergence of biological, social, psychological, and economic factors in families' everyday lives, which constitute a barrier to proper self-care (e.g. Akhter et al., 2016; Li & Whyte, 2021; Tsiouli et al., 2013). It also shows that families with low socioeconomic classification have a harder time managing everyday life with diabetes (Levin et al., 2013; Sanders et al., 2019).

This problem of health inequalities is often addressed by the concept of "health literacy" (e.g. DeWalt & Hink, 2009; Kickbusch et al., 2013; Nutbeam, 2000), covering "*the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others*" (U.S. Department of Health and Human Services, 2024). Research shows a connection between low health literacy, low self-rated health, and unfavorable health behavior (DeWalt & Hink, 2009; Maindal & Vinther-Jensen, 2016). Patients' abilities to understand and act on health information are very important in relation to type 1 diabetes, since 99% of the medical management of diabetes is expected to be carried out by the patients themselves in their daily lives (McLaughlin et al., 2015). However, there is a growing recognition that the capacity to address individual health literacy also depends on organizational health literacy.

Organizational health literacy addresses the health literacy of organizations, recognizing that the healthcare system must have the capacity to adapt its programs to support different patients' abilities to live with their own disease as well as to prevent potential risks (Khorasani et al., 2020; Trezona et al., 2018). This challenges the idea of the patient as solely responsible and gives healthcare systems and professionals a crucial role in helping people cope with chronic and lifelong diseases as a way of reducing health inequalities. It is generally recognized that professionals administer, combine, and use diverse and specialized sources of knowledge in order to decide how practical problems should be handled in specific situations (Grimen, 2008; Molander & Terum, 2008). However, there is little knowledge about how healthcare professionals address complex health issues associated with inequality in practice (Garzón-Orjuela et al., 2020). The aim of this article is to contribute to new knowledge about this.

The empirical material of this article stems from a qualitative case study conducted across two different hospitals in Denmark, where professionals are involved in a special treatment program for children with type 1 diabetes (T1D) and their families who are considered *hard to reach*. The term *hard to reach* represents the healthcare professionals' perception of patients who, for various reasons and despite many attempts, do not benefit from health information, do not comply with normal programs based on self-care, and consequently have a very poor regulation of diabetes. The treatment program is organized as an interdisciplinary healthcare professional effort centered on high-frequency home visits and intersectoral meetings with professionals outside the healthcare system. The treatment program is carried out by doctors, nurses, psychologists, social workers, and dietitians in two treatment teams, cf. the methodology section. The assumption behind the organization of the treatment program is that some families are *hard to reach* and that interdisciplinary knowledge and skills are required in order to improve the health conditions of the child and prevent health inequality (Steno Diabetes Center, 2020).

Based on empirical data consisting of observations of 12 case conferences, this article investigates and answers the following research question: how do healthcare professionals understand children with type 1 diabetes and their families, and how do they consider them *hard to reach?* As a part of the treatment program, the case conferences represent an organizational effort to strengthen healthcare professionals' capacity to understand families' problems with managing diabetes (problem identification), and to solve these problems (problem solving). As empirical material, the case conferences reveal observations and communications about families as *hard to reach*. By analyzing the case conferences, it is possible to develop knowledge about how professionals address complex health issues associated with inequality in practice.

Theory

The research question calls for theory that enables investigation of how healthcare professionals understand and try to solve problems. Therefore, we draw on theories about knowledge practices of professions combined with a system-theoretical perspective on welfare organizations.

Over time, research on professions has offered many and partly conflicting definitions and perspectives on the role and practice of professions in modern society (e.g. Burrage, 1993; Molander & Terum, 2008). However, across these differences, there is a common understanding that professions contribute to solving practical problems for lay people by applying their knowledge base acquired through education (Molander & Terum, 2008). The knowledge base of professions is shaped over time, often by drawing on different disciplines and forms of scientific knowledge, technical-instrumental skill knowledge on how to produce a result, and practical-moral knowledge in the form of ethical considerations and actions (Gilje, 2017). This makes professional knowledge highly fragmented, but more sensitive to the external world and the aim of understanding and finding solutions that might benefit people. Grimen's point is that knowledge is integrated and synthesized in professional practice and varies according to the specific problem that arises in practice (Grimen, 2008). It is thus the nature of the problem that determines which combined knowledge is relevant to solve it. Grimen calls this integration "a practical synthesis" (Grimen, 2008, p.74). A practical synthesis is created in a process where professionals reflect and analyze how a specific problem can be solved in a responsible manner with high professional quality. Therefore, professional actions involve forms of reasoning where discretion and judgment become important (Grimen & Molander, 2008). In relation to this, Grimen argues that professional practice has a normative side, where the professional must balance moral, political, and legal judgments without clear rules for prioritization (Grimen, 2008). Gilje (2017) adds additional dimensions to the action level of practical synthesis. These are "knowing what," which is well-founded knowledge, "knowing how," which is knowledge about how to do something in practice, and theories of "tacit knowledge," which shed light on how knowledge can be implicitly articulated in practice (Gilje, 2017, pp.27-32). A practical synthesis is therefore both heterogeneous through the integration of different scientific disciplines, and also through the use of different practical forms of knowledge that are combined and synthesized in practice. In this article, we perceive the healthcare professionals of the treatment program as a group of experts with different educational backgrounds and theoretical and practical knowledge. The group is working together for the purpose of creating practical syntheses that can improve their understanding of and capacity to solve the problem of children with poor diabetes regulation.

However, the understanding of practical synthesis does not fully capture how different welfare organizations affect professional practice or patients. Therefore, there is a need to add an organizational perspective that focuses on how professionals' ability to understand and solve practical problems is embedded in an organizational context.

The welfare state is differentiated into fairly closed sectors that solve specialized tasks in an organizational context, such as the healthcare system/the hospital services, the social welfare system/social services, etc., which becomes crucial for the self-perception of the organization and how problems are observed and addressed (Luhmann, 2000). Luhmann perceives organizations as social systems that reproduce themselves through communication and decisions for the purpose of coordinating action, and in doing this, they distinguish and draw boundaries between what is internal (system) and external (environment) (Kneer & Nassehi, 1997; Luhmann, 2000). Following this, organizations have functions to fulfill in relation to an environment and form internal programs that specify roles with expectations for behavior and decisions, e.g. of professionals. Luhmann suggests that we study organizations as social systems by deploying the functional method and analysis focused on studying how systems observe and identify problems (problem identification) and solutions to these problems (problem solutions) (Luhmann, 2000). Problem identification contributes to reducing complexity for the system by identifying (and thus delimiting) the problem as something that can be managed and addressed through problem solving, and often this involves understanding and explanation (Luhmann, 2000). However, the way problems and solutions are defined, understood, and explained may vary. This means that there could potentially be other solutions to the same problem, and herein lies a critical potential with regard to identifying alternatives. For example, a basic function and goal of the hospital is to diagnose, treat, and cure diseases. Consequently, this is the main problem in focus prior to solving problems related to health inequalities. That said, professionals at the hospital may observe, reflect on the need, and decide to work with these inequalities in a way that involves both the patients and their families (Andersen, 2008) and may consequently try to create an alternative approach to problem identification and solution.

By using the functional method to analyze how professionals create practical syntheses about *hard to reach* families, we not only gain an understanding of what forms of knowledge are used to create solutions but also learn that these appear in a systemic context that organizes a particular horizon of understanding.

Methods and design

The article is based on data collected by Anette Stamer Ørsted in the PhD project "Better life with diabetes—A case study of the possibilities and obstacles of healthcare systems and healthcare professionals to practically solve a problem with social inequality within healthcare." This study is qualitative and designed with an abductive and dialectical approach (Blaikie, 2000).

Data foundation

The empirical data consists of observations of 12 case conferences (in the following analysis, they will be referred to as "CC") conducted as a part of the treatment program. As mentioned, the case conferences can be understood as the professionals' systematic reflections on problems and solutions related to diabetes treatment in the families (cf. problem identification/problem solution). Therefore, the data is exemplary in illuminating healthcare professionals' syntheses of children and families considered *hard to reach*. Case conferences include doctors, nurses, psychologists, social workers, and dietitians involved in the treatment program at two hospitals, each lasting approximately one hour, conducted between November 2021 and January 2023. The participation of professionals has taken place at each of the two hospitals and has varied due to practical reasons, but several of them were consistently present. Representatives from the specific treatment team (a nurse and a doctor) assigned to the case presented at the case conference were always present. The analysis is concerned with how practical syntheses are formed at the conferences and constitute a common basis for how problems are understood, and possible solutions are proposed. Therefore, the analysis is not concerned with individual differences between the professionals but with recurring problem identifications and solutions. All case conferences were audio-recorded and transcribed, and the first author was present, observing all interactions between professionals.

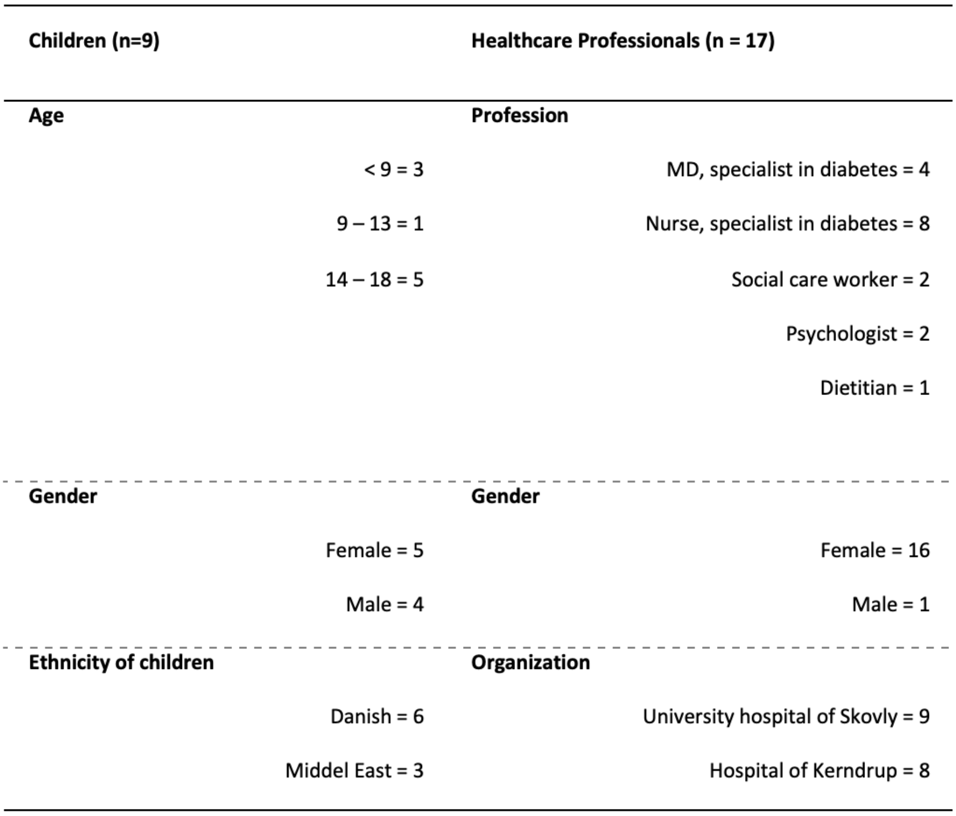
The first author has also followed the treatment program through participation in 10 selected home visits and 21 cross-sectoral meetings throughout the project period, and by conducting 15 interviews with selected families. This data is given a particular focus elsewhere (Ørsted & Engen, 2025; Ørsted, under preparation). This has provided an in-depth insight into how the professionals perceive, synthesize, and identify problems.

Inclusion criteria and participants

The selection of patients for case conferences was made by the healthcare professionals. The 12 case conferences focused on nine out of 19 children included in the treatment program based on the argument that these children and their families were considered *hard to reach*. The tables below provide an overview of the basic characteristics of the children and the professionals (Table 1) and how the professionals characterized the vulnerabilities of the families at the time of inclusion in the treatment (Table 2). The professionals’ characterizations draw on years of knowledge about the families gained from meetings at hospitals, home visits, and cross-sectoral meetings.

Table 1

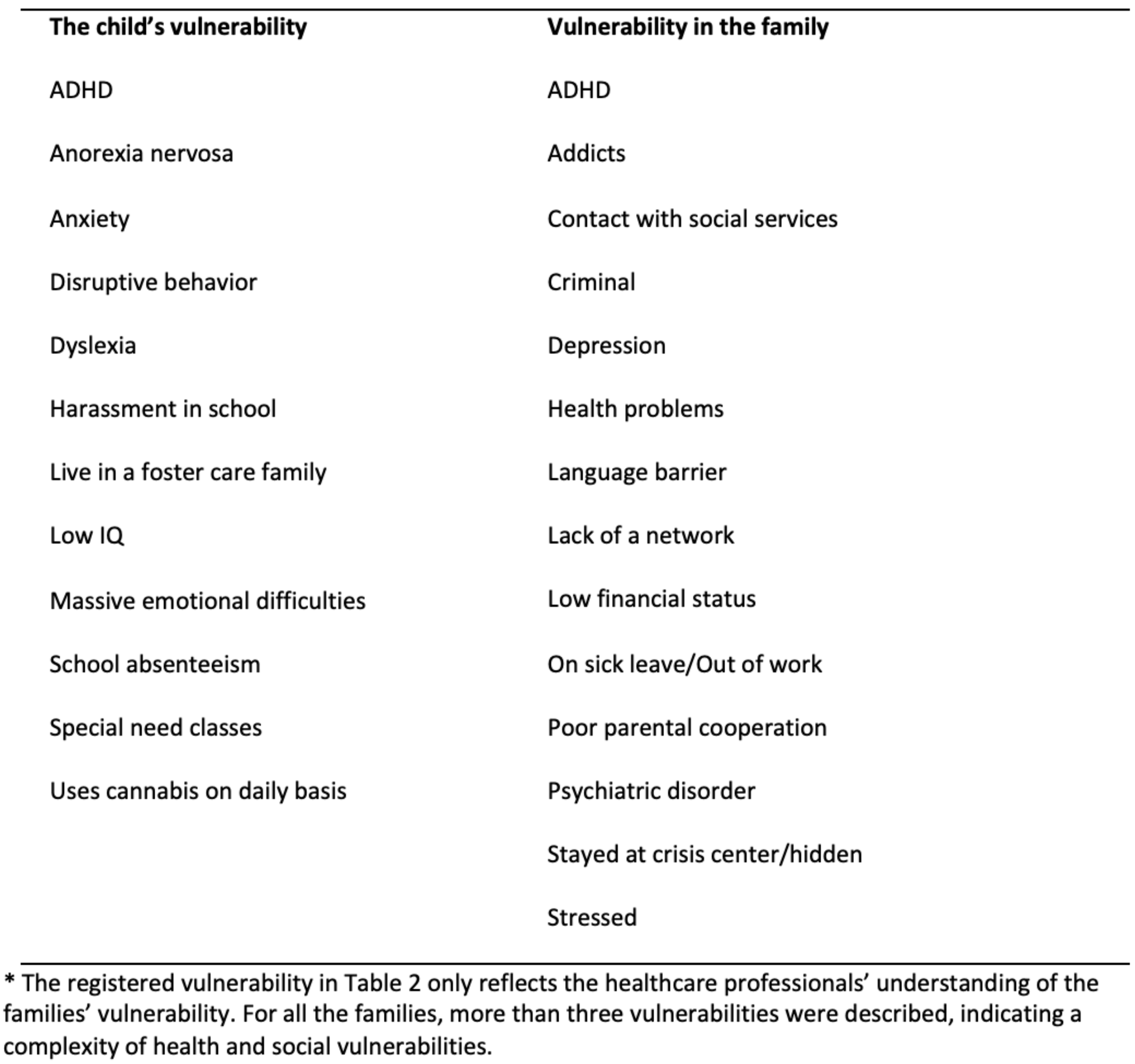
Professionals’ descriptions of children and professionals participating in case conferences



Children (n=9)	**Healthcare Professionals (n = 17)**
Age	**Profession**
< 9 = 3	MD, specialist in diabetes = 4
9 – 13 = 1	Nurse, specialist in diabetes = 8
14 – 18 = 5	Social care worker = 2
	Psychologist = 2
	Dietitian = 1
Gender	**Gender**
Female = 5	Female = 16
Male = 4	Male = 1
Ethnicity of children	**Organization**
Danish = 6	University hospital of Skovly = 9
Middel East = 3	Hospital of Kerndrup = 8

Table 2

*The Professionals' descriptions of the vulnerabilities of children and their families at case conferences**



The child's vulnerability	Vulnerability in the family
ADHD	ADHD
Anorexia nervosa	Addicts
Anxiety	Contact with social services
Disruptive behavior	Criminal
Dyslexia	Depression
Harassment in school	Health problems
Live in a foster care family	Language barrier
Low IQ	Lack of a network
Massive emotional difficulties	Low financial status
School absenteeism	On sick leave/Out of work
Special need classes	Poor parental cooperation
Uses cannabis on daily basis	Psychiatric disorder
	Stayed at crisis center/hidden
	Stressed

* The registered vulnerability in Table 2 only reflects the healthcare professionals' understanding of the families' vulnerability. For all the families, more than three vulnerabilities were described, indicating a complexity of health and social vulnerabilities.

Analysis method

The analysis takes an abductive and dialectical approach where empirical data, professions theories, and system theories are used using the functional method. The purpose is to investigate what healthcare professionals identified as problems and solutions at case conferences and critically reflect on recurring problem understandings and solutions that give rise to a particular understanding of *hard to reach*.

Initially, the analysis was carried out in a process where the first author conducted an inductive and open reading of the case conferences focused on professionals' problem identifications and solutions. The second step of the analysis identified the meaning-bearing units of the problem as they appeared at each of case conferences. The third step of analysis involved organizing the meaning-bearing units into themes across the case conferences. Finally, and based on these themes, the first author made an analytical generalization using the theoretical perspectives of professionals' knowledge-based observations and how organizations shape professionals' views on problems to be solved.

Ethical considerations

The collection of data has included ethical considerations about informed consent and the researcher's position. All informants in this study have been informed verbally and in writing about the purpose of the study and the first author's participation in the activities, and have given written consent for the first author's participation and collection of data in the project. Regular meetings were held between the professionals and the first author, where participation was agreed and discussed.

The study has been reported to the Ethical Research Committee, registered at Aalborg University, Denmark.

Findings

The following analysis presents three understandings of problems and solutions (problem identification/problem solution) that emerge through the shaping of practical syntheses during the case conferences.

Parents as primary collaborators in children's diabetes treatment

Across the case conferences, one understanding of patients as *hard to reach* revolved around a problem identification focused on the collaborative role of parents of young children with diabetes. This problem identification expects parents to take responsibility for daily routines such as blood sugar measurements, carbohydrate counting, and insulin administration by the professionals. Parents are thus the focal point of communication, and collaboration with parents is deemed crucial for healthcare professionals' ability to influence a child's diabetes.

When healthcare professionals identify parents as the primary cause of why families are *hard to reach*, they distinguish between *parents who have resources/lack resources* to manage their child's diabetes. The healthcare professionals indicate that parents' lack of resources hinders the healthcare system's task of treating diabetes. This problem identification draws on the healthcare system's expectation and logic of self-treatment, where parents are perceived as managers and responsible for the child's current and future health (e.g. Mol, 2008). Thus, biomedical knowledge and the ordinary organization of diabetes treatment define that parents must incorporate a medical form of expertise into parenting.

During the case conferences, the professionals elaborate this understanding through practical syntheses that further split this understanding into three different explanations for a lack of resources: (a) a lack of cognitive ability, (b) problems of cooperation among parents, and (c) a lack of willingness and prioritization of resources for diabetes management (difficult to collaborate with).

A first practical medical-oriented synthesis points to the problem of a lack of cognitive abilities as a problem for diabetes care and is evident in the case conferences about a child who has just started primary school. The mother has a chronic disease and a psychiatric disorder. She is on sick leave and has not been at work for an extended period, and due to the child's challenges, the municipality has allocated support to the family. The doctor states, "There are many things that she (the mother) cannot manage [...]. She lacks the energy to handle everything in daily life. She cannot manage both the practical work and taking care of the boy" (CC2, p.3). The nurse elaborates on the problem identification, saying, "Some of it is because she has this disease, but it's difficult to know how cognitively well she is functioning" (CC2, p.3), or "I don't think she does it out of malice, but she cannot handle it" (CC1, p.5).

The professionals assess that the mother lacks resources in terms of following their guidance and making the necessary behavior changes to take care of her son's well-being. With the logic of the healthcare system and in the view of the healthcare professionals, lack of resources is perceived as a lack of health literacy. The mother's lack of cognitive abilities is not compatible with the existing treatment logic's expectations of a high degree of self-care, and, consequently, the family is considered *hard to reach*.

Another practical medical-oriented synthesis regarding parents' resources/lack of resources appears in how the healthcare professionals find it challenging to support children's diabetes treatment due to poor parental collaboration. The nurse describes the problem in this way, "He needs more insulin when he is with mom, but we need to have dad involved in setting it up because he doesn't acknowledge it otherwise" (CC2, p.7), or "We are simply dependent on the parents wanting to collaborate on this, and that we can be in the same room when we discuss further diabetes treatment" (CC1, p.6).

The nurse notes that medical decisions cannot be implemented without collaboration between the parents. They find it problematic that divorced parents don't acknowledge decisions about the child's treatment if they are not consulted individually. The healthcare professionals are challenged by a contextual practical problem (poor parental cooperation) that is difficult to reconcile with the treatment approach. This problem identification involves a form of "knowing that" a lack of cooperation can challenge medical decisions. But they don't seem to "know how" to solve the problem (Gilje, 2017), because a parental conflict is a non-medical issue. The example shows that "knowing that" is necessary but not sufficient without "knowing how" to improve diabetes care. This lack of capacity to find a solution makes the parents *hard to reach*.

A third practical medical-oriented synthesis regarding parents' resources/lack of resources concerns parents of younger children who, despite challenges in daily life, are expected to have resources, but where these are not considered sufficient to manage their children's diabetes. The case conference about a little girl is an example of this. The girl is considered to be relatively well regulated but has fluctuating blood sugar levels and skin problems due to her pump and sensor, and "diabetes is something that is handled with the left hand" (CC3, p.3). The nurse communicates that support for treatment is challenged because the girl's mother takes control of the home visits in a way where communication of the everyday challenges of the family becomes dominant. Faced with this challenge, the doctor wonders about the resources that the mother appears to have when it comes to getting support from the municipality:

> It must be because she has some resources, and there is a massive effort being made to help the family [...] She has some resources that she puts into this and gets what she wants out of it. It's impressive. (CC3, p.7)

The nurse also explains the problem identification, saying, "diabetes is not problematized much compared to how much I think they delve into other problems" (CC3, p.4).

In the quotes above, the mother is observed as a person who might have resources that are not prioritized for managing her child's diabetes. At case conferences, the professionals communicate about the mother's burdens, stress, and lack of energy in daily life as the cause of poor control of the child's diabetes. However, the problem is identified as a lack of prioritization of the child's disease as the cause of lack of compliance with medical instructions for diabetes treatment. This indicates how the healthcare professionals focus on the hospital's objectives and programs on treating diseases.

The analysis shows that the healthcare professionals observe a particular problem related to younger children's disease and treatment that depends on parents' resources/lack of resources to take responsibility for diabetes. Being *hard to reach* is considered to be an individual problem caused by parental resources, whether it's a lack of health literacy, difficult cooperation, or a lack of prioritization. The healthcare professionals reflect on these problems mainly by applying biomedical knowledge, medical programs, and observing through diagnoses and treatment. A basic premise of systems theory is that problems are translated in accordance with the particular horizon and self-description of welfare organizations (Mik-Meyer & Villadsen, 2007). This means that healthcare professionals medicalize and individualize parents who are coping with having children with diabetes. In order to explain why families are *hard to reach*, they tacitly include generalized understandings in our society of what it takes to be a good and responsible parent, emphasizing individual responsibility for self-management, cooperation and capacities to comply with the advice of healthcare professionals, and the healthcare system's development of the patient role (e.g. Hilden, 2002; Petersen & Lupton, 1996).

The professionals' medical-oriented syntheses have implications for the solutions considered appropriate to help the families. For many years, they have tried medical guidance solutions provided by the healthcare system. However, when the problem is observed as a lack of individual resources and responsibility for self-treatment, it becomes difficult for the professionals to see how medical programs can contribute to a solution. They become dependent on knowledge beyond their own system and expertise, cf. social systems theory. Therefore, they try to reach out and mobilize collaboration with other organizations, such as social services, whose task is precisely to support families' resources. Therefore, the problem determines the knowledge to be used to achieve good solutions (Grimen, 2008).

Adolescents with unregulated diabetes and lack of behavior change

The analysis shows that the term *hard to reach* is also related to a category of prolonged unregulated diabetes and a lack of behavior change in adolescence. Common to the young people's health conditions is that they have been hospitalized, and their situation is of great concern among the professionals, who see a potential risk of further hospitalizations and late complications. The young people are in transition to adulthood, where they are expected to handle diabetes regulation to a greater extent on their own, making them the focus of communication in the case conferences.

Initially, the professionals' problem identification regarding the young people revolves around whether they themselves *perceive/do not perceive a problem* with diabetes management. Thus, the young people's awareness of the disease is in focus. The professional's communication reveals a sense of powerlessness, because they do not know how to make the young people recognize the importance of good diabetes management. At the same time their explanations for the lack of behavior vary.

At the case conferences, the professionals compare the adolescent's self-care in diabetes management with their approach to other activities in their lives. This is, for example, the case for a young girl whose life is "filled with everything except diabetes" (CC4, p.1):

> So, all the commitment she demonstrates towards school, she doesn't have that towards diabetes. She has told you several times that it doesn't matter whether she takes a bolus or not. (CC4, p.1)

In the quotes, the nurse distinguishes between the girl's approach to schoolwork versus her self-care in diabetes management. The professionals wonder why there is such a mismatch between the resources and attention she dedicates to school and the responsibility she takes for her disease, indicating that the problem is a talented girl who is not interested in diabetes care. Thus, initially, a biomedical understanding of the young people's physiological needs makes it difficult to accept their behavior. However, it is also recognized that the girl is in a phase of life "filled with everything" other than diabetes, such as doing well in school and having an active life with peers. Thus, the professionals draw on tacit knowledge about young people's everyday life, including how living a "normal" life and taking care of a disease that requires continuous attention and action is a balancing act. The professionals observe a girl with resources, who, nevertheless, is *hard to reach*. The practical synthesis is no longer about the impact of socio-economic factors on health inequality, but integrates common knowledge about what it means for young people to live with chronic disease, a kind of tacit *knowing what* (Gilje, 2017).

The professionals also try to find explanations for the young people's indifference to the disease, theorizing that it is due to lack of resources and poor literacy. For example, a young boy's insulin shock resulting in a physical accident is related to his upbringing and a lack of an adequate role model. The doctor says, "Yes, it's something to do with his personal history. His father also has T1D" *(CC6, p.5).*

The nurse backs this up with a similar comparison between the father and son:

> Another thing is that he (the father) himself has T1D and has previously said that he just has glucose tablets, gummy bears, or candy in his pocket. He can feel when his blood sugar drops, and that's what he has taught him (the son). They don't measure blood sugar. They feel it dropping and then quickly consume carbohydrates. That's the role model he has had his whole life. (CC6, p.7)

In the quotes, the boy's self-care and understanding of managing diabetes are explained by the parents' lack of individual competencies to follow treatment instructions. The listing of the father's use of glucose tablets, gummy bears, and candy, and the idea of being able to control diabetes without measuring blood sugar, shows a practical synthesis depicting a young person suffering from a lack of a parental *role model* capable of introducing *health literacy* in the form of good habits. The healthcare professionals identify a problem of lack of socialization and reproduction of problematic behavior, making the adolescents *hard to reach*.

Over time, there have been various attempts to make the adolescents change their behavior. These have involved frequent home visits, text messages, treatment changes in relation to the pump, counseling programs, changes in the diabetes team, acute hospitalizations, bringing medication, etc. Common for these solutions is that they are based on an individualized medical-oriented synthesis corresponding to the healthcare system's programs and primary knowledge base (cf. Luhmann, 2000). The solutions are targeting young people and focusing on supporting and motivating them to take responsibility for their own disease. In other words, the healthcare professionals try to strengthen young people's health literacy.

During the case conferences, the professionals develop different practical syntheses about the problem of reproduction of problematic behavior, but they find it difficult "knowing how" to link these to solutions appropriate for diabetes treatment. The reproduction of problematic behavior is a problem so complex that a solution requires complex theoretical and practical syntheses (Grimen, 2008), in this case going beyond the healthcare system. They recognize that solutions and "knowing how" must be found with the help of social welfare professionals with knowledge of social problems and the capacity to provide social services that can support diabetes in everyday life. Therefore, in the treatment program, they try to establish cooperation with other welfare organizations, such as the municipality, through networking meetings, meetings with schools, etc., and try to convince them to support diabetes treatment.

Risk of relapse—Diabetes as a piece in a larger puzzle

A third cross-cutting problem is the identification of *hard to reach* families who are challenged by pressing personal, social, and cultural issues beyond the problem of diabetes care. Diabetes treatment is therefore pushed into the background, and the healthcare professionals' focus on a potential risk of relapse to poor regulation in the future.

During the case conferences, the professionals distinguish between families *who are being/not being challenged* by a multitude of problems that hinder diabetes treatment or pose a risk of relapse. The problems are considered to be so massive and pressing that diabetes treatment must await other problems to be solved.

This is evident in one of the case conferences about a young girl. The nurse expresses that she has developed a closeness with the girl and has gained insight into what the nurse calls "psychological terror or violence" of a parent. The nurse seeks guidance on how to handle this knowledge,

> What I would like your advice on is that I get an incredible amount of information, and I just feel like, little girl, this is just not fun. […] I'm thinking, how do I support her in the situation itself—not that it's me who should treat her, but I feel like she tells so many things. (CC8, p.2)

The nurse has developed a close contact with the family, which has given her significant insight into the girl's living conditions. She wants to act based on this lay knowledge but is aware of the limitations due to her role in the healthcare system. This results in a form of powerlessness when it comes to finding solutions. The healthcare professionals recognize the importance of helping the girl, but this is not within the scope of the function and knowledge base of their own organization (Luhmann, 2000). They observe that the solution requires knowledge and interventions from the child protection system, holding the legal authority to act on suspicion of violence.

This need for collaboration with the social welfare system becomes even more evident in the case conference about a girl who has a severe psychiatric disorder that complicates diabetes management. The nurse expresses uncertainty about her role and function in relation to the family:

> Psychiatry comes every other week with a psychologist, a nurse, a social and healthcare assistant, and a social worker, and does more or less the same thing. I think it doesn't make sense if we each sit in our own little backyard and work that way (CC9,pp.3). […] And furthermore, I think it's foolish that I'm trying to use homespun psychology with the tools I have to do it with. Then there are others who are more qualified (CC9, pp.5). […] I actually needed clarification as to what it is I should do? It makes sense to figure out who does what (CC9, p.10). She concludes, I think that diabetes is a very small piece in this whole puzzle. (CC10, p.7)

In the quote above, the problem identification revolves around the nurse's difficulties finding her function and role among all the other professionals from different sectors who offer solutions to the girl's personal and health problems. She suggests that different experts should not perform the same function but should cooperate and create solutions based on their role, expertise, and qualifications to address specific problems (instead of "homespun" solutions). Thus, the nurse observes the girl from a cross-disciplinary perspective, including how the girl's situation arises from a problem of collaboration between systems. From a systemic and organizational perspective, the nurse looks beyond the boundaries of the hospital and identifies an alternative and interdisciplinary solution that draws on knowledge from other systems (Luhmann, 2000).

The professional's observations and recognition of the organizational limitations of the treatment program have implications for the problem solutions identified. The professionals do not communicate about making parents or young people responsible for treatment based on a biomedical perspective. Instead, there is a focus on complex pressing social problems and the role healthcare professionals should play in this context. A nurse points out, "If you could clean up all the other stuff, you could help with diabetes at some point. All the other stuff overshadows much more. Until we get to the diabetes part" (CC10, p.10).

The nurse reflects that it is not possible to progress with diabetes treatment given the turmoil in the girl's life. The nurse observes that the girl's problems are all-consuming for the family's daily life and views the whole family's situation. In this case, it concerns family everyday life, the parents' attachment to the labor market, the girl's social and school life, and their interactions with professionals from the public sector due to the girl's extensive problems. Therefore, the practical synthesis contains lay knowledge about everyday life and mental illness in combination with diabetes, which they transform into a synthesis that results in a prioritization of the sequence of problem solving, starting with pushing diabetes into the background. In this way, diabetes treatment is connected to and aligned with the need for social services and/or interdisciplinary solutions, considering severe troubles in the family's life.

In the observation of families being challenged/not being challenged, the professionals broaden their mono-disciplinary focus on diabetes as a disease and shape their communication around a broader focus on pressing social problems and families' everyday life. Practical syntheses about individuals being *hard to reach* are substituted with professional reflections and lay knowledge about how complex personal and social problems are *hard to reach* for systems, organizations, and professionals. There is a focus on better support to families enrolled in many organizations and on holding other professions accountable as a precondition to prioritizing, targeting, and balancing interventions to specific needs. This does not remove uncertainty with regard to the kind of *know how* needed, but it leads to the healthcare professionals attempting to enable connections to other professions and systems to utilize different systemic capacities and forms of social, biomedical, psychological, etc. knowledge.

Discussion of findings

Our study finds that professionals consider families as *hard to reach* if they do not comply with professional recommendations, and this problem is explained by parental lack of resources, ability, and willingness (problem identification 1 and 2). These problem identifications emerge from medical-oriented syntheses and knowledge stemming from the healthcare professional's role and the function of the healthcare system. However, they also reflect the need for a more heterogeneous knowledge base and consequently, the combination of different forms of knowledge to find solutions, cf. Grimen. The latter appears in problem identifications concerning the reproduction of problematic behavior for diabetes management, ideas about what it is like to be a young person living with a chronic disease, etc. The medical approach distributes responsibility for diabetes care to the individual parent or adolescent. Consequently, it becomes crucial for treatment that patients are capable of both understanding health information and acting on it in a way that leads to good disease management and self-care. Thus, the findings illustrate precisely how ideas of individual health literacy are integrated as a particular *know how* in the healthcare system and how professionals address health inequalities in practice. Other research addressing how differences in treatment arise due to professionals' understandings of patients supports our findings. For example, Shim (2010) argues that professionals' interactions with patients who possess higher "cultural health capital" provide easier access to treatment in the healthcare system (Shim, 2010, pp.3-6). However, theories of professional practice and systems theory enable us to see how professionals can recognize the limitations of their knowledge and capacity to solve complex pressing social and personal problems associated with health inequality. In particular, problem identification three shows that professionals do not only observe the family and individual family members, but also the healthcare system as an organization in an environment of other organizations. In these cases, professionals transcend the idea of individual health literacy as the explanation for inequality in health, and critically reflect on organizational limitations and dependencies with regard to the knowledge of other organizations and professions. They combine different forms of knowledge based on the specific situations of families, thereby using their judgment in accordance with Grimen's idea of practical synthesis (Grimen, 2008) in an attempt to create alternative approaches to problem identification and solutions. Thus, uncertainty and situations where solutions are not evident can lead to professional reflection and a search for knowledge (Nissen, 2015). Seen from a system theoretical perspective, problem identification contributes to reducing complexity for the system by identifying (and thus delimiting) the problem as something that can be managed and addressed through problem-solving (Luhmann, 2000). Thus, critically, one can say that behind the observation of families as *hard to reach* is a healthcare system with organizations and professionals that suffer from problems of reaching out and finding solutions to health inequality. Thus, the role of professionals and the solutions are also *hard to reach*. The analyses therefore indicate that inequality in health is not only a problem of individual patients' lack of health literacy or capital, but also a result of systemic and organizational limitations.

Following the above, strengthening organizational health literacy becomes important. *Organizational health literacy* addresses the health literacy of organizations, recognizing that the healthcare system must have the capacity to adapt its programs to support different patients' abilities to live with their own disease as well as to prevent potential risks. An organization characterized by organizational health literacy, according to the literature, focuses on improving patient engagement and literacy in the healthcare process. It is considered an organizational priority. There is a particular focus on providing health information, training staff in health communication, and addressing health literacy with specific management activities (Khorasani, 2020). The findings in this article can contribute to the very open definition of organizational health literacy when it comes to the target group of patients with complex and interacting social and health problems. Here, the results show that organizational health literacy also must involve a reflective, coordinated, and targeted effort in the organizational interface between health and social systems. This can be done by taking into account the concept of boundary spanning. Boundary spanning is about solving complex problems and managing interdependencies at the interface between organizations and interprofessional knowledge (Van Meerkerk & Edelenbos, 2021). Boundary spanners are professionals who "pro-actively scan the organizational environment, employ activities to collect information and to gain support across organizational or institutional boundaries, disseminate information, and coordinate activities between their 'home' organization or organizational unit and its environment, and connect processes and actors across these boundaries" (Van Meerkerk & Edelenbos, 2021, p.1439). Boundary spanning can strengthen organizational health literacy if organizations and professionals learn from and apply each other's knowledge and responsibilities in a coordinated and holistic way based on patients' situations and needs. Given the cross-border nature of social and health problems, further research on inter-organizational health literacy and boundary spanning is needed. It will be explored in the PhD project "Better life with diabetes—A case study on the opportunities and barriers for health systems and professionals in solving a problem of social inequality in health in practice."

Conclusion

The aim of this article was to investigate how healthcare professionals identify, reflect on, and solve problems with patients considered *hard to reach* and therefore pose a problem of health inequality. The analysis shows that professionals consider families *hard to reach* if they do not comply with professional treatment recommendations. This can be explained by their lack of resources, ability, willingness, and/or complex social and personal problems of the family members. These understandings and explanations rely on practical syntheses integrating scientific medical knowledge about chronic diseases and treatment prescriptions with lay knowledge about specific families, their personal and social problems, and capacities for managing diabetes. Thus, they combine different forms of knowledge according to the specific problem that arises in practice in line with the idea of practical synthesis (Grimen, 2008). The analysis also shows that professionals recognize that people's complex personal and social problems cannot be solved solely by the healthcare system. Solutions to health inequalities create a dependency on other professionals and organizations with other functions and knowledge. Therefore, solutions must not only focus on individual health literacy, but also on organizational health literacy, which expands the perspective to be intra-organizational. The article's findings suggest that the capacity to manage individual health literacy depends just as much on organizational health literacy.

Strengths and limitations

The study offers a unique insight into the complexities of how professionals address health inequalities in practice. Methodologically, a strength of this study is that the results are understood in the context of the extensive empirical material collected through interviews with families, focus groups with healthcare professionals, and observations from cross-sectoral meetings. However, theories of professional practice and systems theory are not focused on the experiences of patients, including how they observe and evaluate the encounter with the healthcare system. This is where phenomenological perspectives on patients' lived lives with diabetes can be combined. This is explored in the article "Everyday life with diabetes in families in vulnerable life situations—The daily balance of the responsibility for selfcare" (Ørsted & Engen, 2025).

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References

Akhter, K., Turnbull, T., & Simmons, D. (2016). Influences of social issues on type 1 diabetes self-management: Are we doing enough? *Practical Diabetes, 33*(9), 307–312a. https://doi.org/10.1002/pdi.2061

Andersen, N. Å. (2008). Velfærdsledelse: Diagnoser og udfordringer [Welfare management: Diagnoses and challenges]. In C. Sløk, & K. Villadsen (Eds.), *Velfærdsledelse [Welfare management]* (pp. 33–68). Hans Reitzels Forlag.

Blaikie, N. (2000). *Designing social research: The logic of anticipation.* Polity Press.

Borschuk, A. P., & Everhart, R. S. (2015). Health Disparities among Youth with Type 1 Diabetes: A systematic review of the current literature. *Families, Systems, & Health, 33*(3), 297–313. https://doi.org/10.1037/fsh0000134

Burrage, M. (1993). From practice to school-based professional education: Patterns of conflict accommodation in England, France, and the United States. In S. Rothblatt, & B. Wittrock (Eds.), *The European and American University since 1800* (pp.142–187). Cambridge University Press. https://doi.org/10.1017/CBO9780511720925.005

DeWalt, D. A., & Hink, A. (2009). Health literacy and child health outcomes: A systematic review of the literature. *Pediatrics, 124*, S265–S274. https://doi.org/10.1542/peds.2009-1162B

Garzón-Orjuela, N., Samacá-Samacá, D.F., Luque Angulo, S.C., Mendes Abdala, C.V., Reveiz, L., & Eslava-Schmalbach, J. (2020). An overview of reviews on strategies to reduce health inequalities. *International Journal for Equity in Health, 19*, Article 192. https://doi.org/10.1186/s12939-020-01299-w

Gilje, N. (2017). Profesjonskunnskapens elementære former [The Basic forms of professional knowledge]. In S. Mausethagen, & J. I. Smeby (Eds.), *Kvalifisering til profesjonell yrkesutøvelse [Qualification for professional practice]* (pp.21-33). Universitetsforlaget.

Grimen, H. (2008). Profesjon og kunnskap [Professions and knowledge]. In A. Molander, & L. I. Terum (Eds.), *Profesjonsstudier [Professional studies]* (4th ed., pp.71-86). Universitetsforlaget.

Grimen, H., & Molander, A. (2008). Profesjon og skjønn. [Profession and discretion]. In A. Molander, & L. I. Terum (Eds.), *Profesjonsstudier [Professional studies]* (4th ed., pp.179-196). Universitetsforlaget.

Hilden, P. K. (2002). Teknologi og kultur—HbA1c, selvbehandling og type 1-diabetes [Technology and culture—HbA1c, self-treatment, and type 1 diabetes]. *Tidsskrift for den Norske Legeforening, 122*(1), 69–72.

Khorasani, E. C., Sany, S. B. T., Tehrani, H., Doosti, H., & Peyman, N. (2020). Review of Organizational Health Literacy Practice at Health Care Centers: Outcomes, Barriers and Facilitators. *International Journal of Environmental Research and Public Health, 17*(20), 1–16. https://doi.org/10.3390/ijerph17207544

Kickbusch, I., Pelikan, J. M., Apfel, F., & Tsouros, A. D. (2013). *Health literacy: The solid facts.* World Health Organization Regional Office for Europe. https://iris.who.int/bitstream/handle/10665/128703/e96854.pdf

Kneer, G., & Nassehi, A. (1997). *Niklas Luhmann—Introduktion til teorien om sociale systemer*. [Niklas Luhmann—Introduction to the theory of social systems] (1st ed.). Hans Reitzels Forlag.

Levin, L., Kichler, J. C., & Polfuss, M. (2013). The Relationship Between Hemoglobin A1C in Youth with Type 1 Diabetes and Chaos in the Family Household. *The Diabetes Educator*, *39*(5), 696–704. https://doi.org/10.1177/0145721713496872

Li, A., & Whyte, M. (2021). Disparities in Diabetes Care. *EMJ Diabetes*, *9*(1), 92–101. https://doi.org/10.33590/emjdiabet/21-00194.

Luhmann, N. (2000). *Sociale systemer: Grundrids til en almen teori [Social systems: Outline of a general theory]* (1st ed.). Hans Reitzels Forlag.

Maindal, H. T., & Vinther-Jensen, K. (2016). Sundhedskompetence (Health literacy)—Teori, forskning og praksis [Health Literacy—Theory, Research and Practice]. *Klinisk Sygepleje, 30*(1), 3–16. https://doi.org/10.18261/issn.1903-2285-2016-01-02

Martin, H. M., & Topholm, E. H. (2020*). Sårbarhed og diabetes: En litteraturgennemgang [Vulnerability and diabetes: A literature review].* VIVE-Det Nationale Forsknings- og Analysecenter for Velfærd [The National Research and Analysis Center for Welfare]. https://www.vive.dk/media/pure/14921/4119732

McLaughlin, S., Chaney, D., Belton, A., & Garst, J. (2015). *International standards for education of diabetes health professionals*. International Diabetes Federation. https://idf.org/media/uploads/2023/05/attachments-34.pdf

Mik-Meyer, N., & Villadsen, K. (2007). *Magtens former: Sociologiske perspektiver på statens møde med borgeren (1. udgave) [Forms of power: Sociological perspectives on the encounter between the state and the citizen (1st ed.)].* Hans Reitzels Forlag.

Mol, A. (2008). *The logic of care: Health and the problem of patient choice.* Routledge. https://doi.org/10.4324/9780203927076

Molander, A., & Terum, L. I. (2008). Profesjonsstudier—en introduksjon.[Professional studies—An introduction] In A. Molander, & L. I. Terum (Eds.), *Profesjonsstudier [Professional studies] (*4th ed., pp.13-27*)*. Universitetsforlaget.

Nissen, M.A. (2015). Viden om viden og kvalitet [Knowledge about knowledge and quality]. In M. Harder, & M.A. Nissen (Eds.), *Socialt arbejde i en foranderlig verden [Social work in a changing world]* (1st ed., pp.119-134). Akademisk Forlag.

Nutbeam, D. (2000). Health Literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International, 15*(3), 259–267. https://doi.org/10.1093/heapro/15.3.259

Petersen, A. R., & Lupton, D. (1996). *The new public health: Health and self in the age of risk*. Sage Publications.

Sanders, T., Elliott, J., Norman, P., Johnson, B., & Heller, S. (2019). Disruptive illness contexts and liminality in the accounts of young people with type 1 diabetes. *Sociology of Health & Illness*, *41*(7), 1289–1304. https://doi.org/10.1111/1467-9566.12906

Shim, J. K. (2010). Cultural health capital: A theoretical approach to understanding health care interactions and the dynamics of unequal treatment. *Journal of Health and Social Behavior, 51*(1), 1–15. https://doi.org/10.1177/0022146509361185

Steno Diabetes Center (2020). Initiativbeskrivelse for tilbud om hjemmebesøg til sårbare patienter (børn og unge) og familier [Initiative description for offering home visits to vulnerable patients (children and young people) and families]. Steno Diabetes Center.

Trezona, A., Dodson, S., & Osborne, R. H. (2018). Development of the organisational health literacy responsiveness (Org-HLR) self-assessment tool and process. *BMC Health Services Research, 18*(1), 694. https://doi.org/10.1186/s12913-018-3499-6

Tsiouli, E., Alexopoulos, E. C., Stefanaki, C., Darviri, C., & Chrousos, G. P. (2013). Effects of diabetes-related family stress on glycemic control in young patients with type 1 diabetes systematic review. *Canadian Family Physician*, *59*(2), 143–149. https://pmc.ncbi.nlm.nih.gov/articles/PMC3576940/

U.S. Department of Health and Human Services (2024, August 1). *History of Health Literacy Definitions.* Healthy People 2023. https://health.gov/healthypeople/priority-areas/health-literacy-healthy-people-2030/history-health-literacy-definitions

Van Meerkerk, I., & Edelenbos, J. (2021). Becoming a competent boundary spanning public servant. In H. Sullivan, H. Dickinson, & H. Henderson, (Eds.), *The Palgrave Handbook of the Public Servant* (pp. 1437–1452). Palgrave Macmillan. https://doi.org/10.1007/978-3-030-29980-4_39

Walker, A. F., Haller, M. J., Gurka, M. J., Morris, H. L., Bruggeman, B., Miller, K., Foster, N., Zabala, A. C., & Schatz, D. A. (2019). Addressing health disparities in type 1 diabetes through peer mentorship. *Pediatric Diabetes, 21(*1), 120–127. https://doi.org/10.1111/pedi.12935

Ørsted, A. (under preparation). Bedre liv med diabetes—et casestudie om sundhedssystemer og -professionelles muligheder og barrierer for i praksis at løse et problem med social ulighed i sundhed. [Better life with diabetes—A case study of the possibilities and obstacles of healthcare systems and healthcare professionals to practically solve a problem with social inequality within healthcare].

Ørsted, A., & Engen, M. (2025). Hverdagslivet med diabetes hos familier i sårbare livssituationer—Den daglige balancering af ansvaret for selvbehandling [Everyday life with diabetes in families in vulnerable life situations—The daily balance of the responsibility for selfcare]. *Tidsskrift for Forskning i Sygdom og Samfund [Journal of Research in Disease and Society],* 43, 110-134. http://DOI: 10.7146/tfss.v25i43.147327