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Making the best of it: Practical wisdom in professional care for adolescents with type 1 diabetes mellitus

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Abstract

Multidisciplinary professional care for adolescents with type 1 diabetes mellitus has been supported by detailed international consensus guidelines since 1995. However, several professional authors have argued that it takes more than excellent guidelines to give good care also in a moral sense in daily practices. In this article, we report on an exemplary case study into the adolescent diabetes outpatient clinic of a Dutch general hospital, with the aim to explore how practicing professionals enacted the attuning of general guidelines to individual patients in their specific contexts. To realize this aim, we have conducted ethnomethodologically inspired, participatory observations, and an abductive analysis, using tools that have been derived from grounded theory. We carried out the inquiry using the heuristic lenses of relationality and practical wisdom. In addition, we used care ethics and practice theory as theoretical frames. Relationality and practical wisdom appear to be strong vectors of good care in everyday diabetes practice.

Introduction

The problem: Friction between guidelines and practice

In 1995, the International Society for Pediatric and Adolescent Diabetes (ISPAD) [1] published consensus guidelines for the medical care of children and adolescents with diabetes mellitus, and these guidelines have been regularly updated and complemented. The latest evidence on the disease has been incorporated into the guidelines, in combination with the expert knowledge of a multi-disciplinary group of experienced professionals. The guidelines have been adjusted to the characteristics of local, regional, and national conditions. For instance, the American Diabetes Association published 'Children and Adolescents: Standards of Medical Care in Diabetes 2018 [2], whereas in the Netherlands, the Dutch Diabetes Federation in coopera-

tion with the Dutch Association of Pediatric Medicine, produced a Standard of Care (2009) [3] based on these guidelines. In the formulation of ISPAD the ultimate goal of care for adolescents with diabetes mellitus is: "High quality of life, normal growth and development, and lower attainable risk of acute and longterm diabetes complications". This goal describes the perfect, successful end point of professional diabetes care.

The standards set out in the guidelines are biomedical target values of good care, described as physical, biochemical and psychosocial characteristics such as: Optimal average blood glucose level (HbA₃c 58 mmol/mol); normal growth and weight; no acute or late complications of the disease; self-management and independence. The guidelines also include standards for procedures and planning of care (frequency of check-ups; **Citation:** Bontemps-Hommen CMML, Vosman F, Baart A. Making the best of it: Practical wisdom in professional care for adolescents with type 1 diabetes mellitus. J Clin Images Med Case Rep. 2021; 2(4): 1233.

multi-disciplinary teams; use of plans for education and care). Inevitably, these guidelines are based on average patients. The guidelines do not discuss how possible discrepancies between standard and individual patients should be bridged.

As it happens, however, authors from medical [1-11] and from non-medical backgrounds [12-18] have argued that practicing professionals need more than these useful guidelines to give good care to their patients. Several authors have argued that practitioners should be able to acquire adequate knowledge about the individual patient in her situation and context. The authors state moreover, that other modes of knowledge are required than evidence as it appears in the guidelines, or basic scientific medical knowledge, for instance intuitive, and experience-based knowledge.

Furthermore, in these publications is stated that professionals should focus not only on realizing medical standards, but also on *meeting moral norms*, that is to "Appreciate what is good for a patient as a person, not merely as a biological being" Kaldjian [6, p. 73]. This is the *ethical* dimension of care, according to Kaldjian.

Finally, several authors have *qualified the ideal goal* of professional diabetes care. For example ledema, Mesman and Carroll [19, p. 81] have argued that daily practice is: "A mode of practice that aligns with what is possible more than with what is formally required."

Consequently, there appears to be a problem for professional practices of how to determine the correct ratio between the general knowledge of the guidelines and personal and situational knowledge about the individual patient [16]. Or, in addition: how to find the correct balance between biomedical standards and moral norms in individual cases [20]; or how to transform ideal purposes into achievable goals [21]. This problem has led to the following research questions:

Research questions

- 1. How is a balance enacted between personal and situational patient knowledge and bio-medical patient knowledge as prescribed in the guidelines, through ordinary actions within an everyday diabetes practice? This question will be addressed specifically for a) individual practitioners, b) the diabetes team, and c) the way the infrastructure of the practice facilitates this.
- 2. How is (are judgements on) morally good care enacted, in relation to the medical standards of the guidelines through ordinary actions within an everyday practice?. This question will similarly be addressed specifically for a, b and c (see above).
- 3. How is a balance established between agreed, appropriate goals for individual patients in their specific contexts and the general goals laid down in the guidelines? This question will, once again, be addressed specifically for a, b and c.

Before we describe the research method we have used in this study, we will introduce the conceptual lenses through which we observed the practice.

Our perspective: Care ethics, relationality, care practices and practical wisdom

First, we approached our subject from a care ethical perspec-

tive. In the context of the current study, this specifically means that we regard giving professional care as a relational activity, in which "Care (...) results, becomes structured and relevant from thinking, exploring and steering relationally" [22, p. 74]. Furthermore, we argue that it is distinctive and relevant for patients in care relationships to be vulnerable and dependent, because they are ill and are suffering [23].

Second, we studied medical care as a *practice*, and we have used this term as it is defined in certain practice theories. Nicolini [24, p.220] has described practices as "Real time doing and saying something in a specific place and time." (Also see [25,26]). Practices of care are enacted and re-enacted not by isolated individuals, performing alongside each other, but in complex networks of and interactions between actors, including patients in their contexts, and material and immaterial non-human actors [27,28]. Moreover, Vriens, Achterbergh and Gulpers [29], as well as Moore [30] and Moore and Beadle [31] referring to MacIntyre [32], have emphasized the relevance of the infrastructure in which practices are embedded. They advocate the alignment of organizational purposes with the 'Internal Goods' of embedded practices.

Third, we have aimed at understanding professional practices 'on their own terms' [33,34,16,24,26,35,36], i.e. on the basis of the rationality 'Imbedded' in these practices, a rationality which might be different from that of biomedical sciences. Mol [16] has described this rationality as 'The logic of care giving'; others have mentioned practical wisdom as its distinctive characteristic [37,6,7,38,10,39]. Our supposition has been that, by observing through the lens of practical wisdom, it is possible to make the 'Logic', or the 'Grammar' of the practice perceptible, and to describe it subsequently [33]. We define practical wisdom heuristically as: The capability which emerges in acting jointly within medical practices, of knowing how to remain focused on achieving the good for every individual patient, in ever changing situations within the context of the practice and its telos and of how to accomplish this by the most appropriate means, while dealing with complexity and institutional and systemic pressure" [37]. We regard 'The Good' as specific to individual patients in their contexts and situations, as variable, and as something that can only be validated retrospectively, by the experience of the care recipient [40,41].

Our hypothesis is that observations made through the observational frameworks of *relationality, practices* and *practical wisdom*, will enable us to identify new and unexpected issues in the practice of care for diabetes patients, and to learn how good care is enacted in professional practices.

The following section will set out the research methodology that we have devised to answer the research questions.

Method

An exemplary case study

We have opted to conduct, a qualitative, exploratory case study, through direct observation of an adolescent diabetes outpatient clinic (practice) in a Dutch general hospital. We approached this complex case (practice) according to Stake's constructivist-interpretivist orientation [42] and as a complex and integrated whole according to Anderson, et al [43]. We chose

ambulatory care for patients with the *chronic disease* of type 1 diabetes mellitus, because this is a disease that has a great impact on patients' daily lives and context [44,15,16]. In addition, it is a difficult task to achieve the stable regulation, that the guidelines recommend. We then chose the age group of *adolescents* – children in the transition period to maturity, aged 12 to 21 – because this group's physical, mental and social stability is under pressure during this phase, and the patients must establish ways of coping with the disease, independent from parents or counsellors [45]. Supporting adolescents with diabetes therefore constitutes a real challenge for practitioners; this makes the case an exemplary one [41]: "The exemplar methodology is a sample selection technique that involves the intentional selection of individuals, groups, or entities that exemplify the construct of interest in a highly developed manner" [46, p. 1].

An ethnomethodologically-inspired approach

Nicolini [24] has described "Ethnomethodologically (EM)-inspired approaches", alongside other methods, which are 'Slow' and 'In-depth', and enable observation of details and specific particulars of a situation, as appropriate for research of practices. According to Nicolini, an EM-inspired approach focuses on accurately re-constructing a) the means practitioners use to accomplish actions together and b) the organization of relationships and interactions. Patton [47] has emphasized that EM is focused on making the tacit knowledge of a practice explicit [48], and on making sense of daily activities.

Nicolini's advice is to focus the research of practices not only on actions, interactions, and meanings, but also on "The land-scape of tools, artefacts, and resources" [24, p. 223] and on the way these material agents are integrated. He also recommends taking note of the observable goal orientation, morality, and concerns within the practice.

Participatory study

Direct observation of practices, 'Fieldwork', consists of "the circumstance of being in or around an on-going social setting" [47, p. 262]. This implies a more or less participatory approach. Patton has listed many advantages of direct observation, including being able to observe matters of which the participants are not aware in a practice, issues participants do not want to talk about in interviews, and issues that go beyond the participants' selective perception, thus obtaining a more complete overall image [47, p. 27].

At the time the observations were carried out, the first researcher worked as a pediatrician in the pediatric practice concerned, but she was not a member of the diabetes team. She was therefore both involved with, and at a distance from the team that was under study. According to Eikeland and Nicolini [33], commitment to and active participation at a practical level during a well-defined period have the advantage that the researcher can better observe the sought-after 'Grammar' of the practice. They have advocated "A new type of 'Detached' research aiming at knowledge and understanding from within the knowers' own practice, not from a segregated position outside" [33, p. 7]. The purpose of this type of research is twofold: to produce a new type of theory, that is comparable to the grammar of language; and to provide "A tool for insight" into the practice to practitioners. However, our modest goal was only to acquire some important theoretical insights.

As an insider and because of her experience, the first re-

searcher had an understanding of the culture, the structures, and the context of the practice. That is why she must be considered as competent to devise adequate and rich interpretations of the data. However, her double role (as a colleague and a researcher) may also have led to bias and blind spots [47,49]. Thus, safeguards had to be included to ensure the internal validity and trustworthiness of the study. First, we applied investigator triangulation: the critical co- evaluation of the observations and analysis by the two co-authors, who are ethicists and who are not affiliated with the hospital in question, although they are experienced researchers in other hospitals. Moreover, the researcher returned the entire research report to a group of seven professionals from the diabetes practice in question: member checking in a focus group [50]. Practitioners were asked to check facts and interpretations and to add essential information they were missing. Results were adapted after reflection and deliberation within this group.

Permission was obtained from the Institutional Ethical Committee and the Hospital Board to carry out this study. All patients involved, their parents and the practitioners gave their verbal informed consent, after they had been informed of the aim and the methods of the study. The data will be presented in de-identified form. In order to protect the participants' privacy, pseudonyms have been used, and where necessary, factual details have been changed.

Research data

Within the time-frame of three years (2014 to 2016), the first researcher gathered the research data by observing ten consultations for diabetes patients, during which on average five patients were seen, including preparatory discussions and final evaluations. Doing this, she was able to observe the five pediatricians and the four diabetes nurses who were members of the diabetes team, and 42 adolescent patients, some of them twice. In addition, she observed four contacts between patients and a dietician, and three between patients (accompanied by a parent, or by the whole family) and a psychologist. She followed a patient after the diagnosis had been made, during the first two months of ambulatory care. She observed the first contact between an adolescent in transition and the internist. If necessary, she interviewed practitioners informally immediately after a consultation, to ensure proper understanding. Furthermore, she interviewed one of the pediatricians, two very experienced diabetes nurses, and the child psychologist, with the aim to gather additional information, that could not be derived from available data (for example regarding their specific education). She attended two formal (quarterly) and three informal (weekly) team meetings; in addition, three educational meetings, and the presentation to practitioners and patients of a new device for glucose monitoring. She studied all available documents, such as the education plan per year group of 8 to 18-year-olds, individual care plans, and quality-of-life-questionnaires for children and parents. She consulted national and international guidelines, health insurers' compensation rules, and quality and safety standards.

She made notes (field notes) of the observations, recorded the conversations and made verbatim transcripts of these [51].

Method of analysis

We chose to conduct an abductive analysis, using elements of grounded theory [52], modified according to Charmaz's constructivist views [53-55], such as the specification of 'sensitizing

concepts'; coding - initial, focused and theoretical -; memoing (researcher's notes to document a line of thought and decision making); and constant comparison, to guarantee the rigor of the analysis, and to allow for conclusions to be drawn on the concepts of relationality and practical wisdom, that would be grounded in the data.

Performing an abductive analysis means that a researcher enters the field with preconceived theoretical ideas, not as a theoretical 'Tabula rasa', and aims for new theoretical insights from the observed practice. Abductive analysis was improved by using the methodological steps of revisiting (over time, repeatedly re-evaluating data) and de-familiarizing (regarding data as deviant and strange) according to the recommendations of Timmermans and Tavory [56] and Timmerman et al [41].

After a first analysis of part of the data had been completed, the first researcher drew up a first draft text, which she critically discussed with the other researchers. The discussions yielded new insights and problems; subsequently, she repeated the analysis and adjusted the text. This was repeated until all data were analyzed and saturation was achieved. Finally, she presented the entire report to the focus group, and adapted the text again.

In the following section, we will represent the results of the observations we made through the heuristic lenses of relationality and practical wisdom, and of the subsequent analysis, based on the three research questions, each broken down for practitioners, team, and infrastructure.

Results

First research question: How is a balance enacted between personal and situational patient knowledge, and bio-medical patient knowledge as prescribed in the guidelines, through ordinary actions within this diabetes practice?

This question will be addressed specifically for

Individual practitioners

All practitioners appeared to have explicit knowledge of the latest guidelines. In addition, these guidelines were easily available electronically. Enacting a proper balance appeared to depend on *gathering*, *integrating* and *applying knowledge* in an iterative movement.

Gathering knowledge: the 'regular team' (pediatrician [PE] and Diabetes Nurse [DN]) assigned to every patient, usually knows its patients from the beginning of the illness. During the intensive support that is offered at the emergence of the diabetes, professionals become acquainted with the patient's living conditions, her personal characteristics, her school and leisure activities; they record this in the patient's file. Moreover, the regular team prepares each consultation contact, for instance by reading laboratory results and measurement results sent in (biomedical knowledge), and by reviewing the most recent arrangements made with the patient. During this preparatory deliberation, the team anticipates the consultation by sharing all kinds of knowledge gathered since the last consultation and by considering common policy. "What does this mean?" "Which of us will join?" "How are we going to proceed?" The same procedure is followed for annual check-ups, but in the larger team. In addition, the entire team as a whole informally discusses current patient issues at a fixed time every week.

We observed that, during the consultations, practitioners

attempted to increase personal knowledge, and knowledge about the patient's living context by *asking* the patients *many questions* and by asking *more questions* if they perceived any difficulties or signals of ambiguities. In doing so, they not only concentrated on facts, but first and foremost on the *patient's perspective* on this factuality.

Bram, who has an insulin pump, has started secondary school this year. PE: "How is school?" B: "Yes, fine." PE: "School fun?" B: "Yes, It is." PE: "Tell me, did anyone from your previous school go to the same school?" etc. Later on in the conversation PE: "Does anyone care, that you are different from the others? Does it bother you?" B: "Yes, it does, cause I'm often too low, for instance, when I'm going to play soccer or something like that.." PE: "Yes, you spend a lot of time outdoors don't you? Hanging out outside?" (....) "Is that why it's more difficult for you to know beforehand that you are going to play outside? Is that why?" B: "Yes, it is."

Integrating/applying: The following example shows that the practitioners include knowledge of the person (PE: "Nick has the characteristics of autism — the outcome of a psychological inquiry -. This will lead to problems with his diabetes because he is unable to put things into perspective") in the way they deal with a bio-medical patient problem.

Nick, who has an insulin pump, is upset, because he regularly, but not always has a hypoglycemia when he returns from his weekend job in the library. The diabetes nurse, like a detective, goes through the possible causes of the problem with him: his activities at work; the circumstances under which the hypo attacks occur; when and what he eats and when he injects insulin and how much. She then discusses in detail which pump settings he can use to take less insulin on Saturdays and how he can check when and whether the blood glucose levels are acceptable without them interfering with his work.

The practitioners also communicated medical-scientific knowledge, dosed and tailor- made, during consultations: Too much protein in the urine may be an indication of too high blood glucose levels over a longer period; even if patients have a glucose sensor, blood glucose levels must still be checked three times a day through a finger prick in order to calibrate the sensor; the areas used for finger pricks and for injections of insulin must be changed regularly; the dietician takes the patient through a checklist she has made to intercept hypo attacks.

Bio-medical patient knowledge is derived from physical examinations, lab results and digital graphs. The division of tasks between pediatrician and diabetes nurse, that we observed, is as follows: The pediatrician does the physical examination, according to a fixed pattern (for instance, she always checks pricked areas), draws attention to medical points of importance, like blood pressure or co-morbidity with diabetes (coeliac disease) etc. The diabetes nurse, together with the patient, looks at computer diagrams of blood glucose levels, intake of carbohydrates in food and levels of insulin injected; she also discusses the right use of materials. Other tasks were mutually interchangeable. The physical examination proved to be an intimate moment between doctor and patient, and regularly was an opportunity to gather more specific knowledge about the patient. "Where did you get that beautiful tan?" "Hey, you always prick in the same place; there is even a little wound. Why is that?" "I Can't see any pricked areas on your tummy; do you ever prick there?" The physician 'Feels' any tension that the patient may display, observes a patient blush, tremble or perspire.

Conversely, because of the increased perception of vulnerability, barriers sometimes disappear, allowing patients to express themselves more easily.

It is remarkable, that when they inspected their personal graphs on the screen with the DN, patients seemed to observe themselves from a distance, and it was precisely this distance that seemed to facilitate honest conversation about the results.

Hans, who has an insulin pump, and is a secondary school student: DN: "Do you see those strange outliers — 20 on one occasion and 16 on another. Are you able to explain that in retrospect?" H: "Yes, I am, it is from injecting too late for a snack or injecting not at all on every occasion ...that happens from time to time; I'm too lazy, or I forget it, or I think it's OK" (....) DN: "So, there is usually an explanation? Not that you are saying: how is that possible? I'm such a loser?" H: "Well, it's usually that I take a snack and forget to inject."

Applying: We regularly heard practitioners ask: "Are you comfortable pricking your finger and injecting in class?" When they found that a patient was worried about something, or was unable to solve some recurring problem they, generally, did not offer directive recommendations in accordance with the guidelines. Instead, they often worked on the basis of their knowledge of the patient-in-context to stimulate her to find an appropriate solution herself. Thus, they encouraged the patient's growing independence.

The pediatrician discusses the weekend with Tom. "If you begin your Saturday by working (at home on the farm), and then go mountain biking, your injection schedule should really look very different than on schooldays. How would it be different?"

Summary: The practitioners had ready knowledge of the guidelines. Additionally, from the first introduction of a new patient on they acquired and updated their personal and contextual knowledge of the individual patient by asking questions, asking further questions, deliberating with their colleagues in the diabetes team, and consulting notes laid down in the electronic patient record. Biomedical patient knowledge was gathered from physical examinations, lab results, measurement results and digital graphs. They integrated and used that knowledge when giving advice and when choosing an appropriate approach.

The diabetes team

The members of the smallest team shared knowledge and experience on the spot, when they met the patient together; that is why they often succeeded in giving complementary guidance. In the following example, the DN's input of experience-based knowledge (routinizing an activity that is experienced as disagreeable, works better than having to take a decision over and over again) and the PE's input, intuitively linking motivation and result, mutually reinforced each other.

Independent Ruud, who has an insulin pump, has an HbA₁c of 65 mmol/mol. But he is not satisfied with this reasonable result, because he is struggling hard to achieve good regulation. He measures his blood sugar at least six times a day, he injects insulin when he eats an additional snack etc. Nevertheless, he has one hypo attack on average per week, which causes him a lot of problems. The DN, thinking practically, discovers that this is possibly caused by the fact that he does not change his infusion device often enough, because he finds that unpleasant. She advises him to reduce his aversion by turning this activity into a

routine, changing it at fixed times, three times a week. The PE addresses Ruud in a different way: "There's one thing I maybe think is still quite a challenge: you're really putting in a lot of effort, and you'd like to ultimately see... you'd like it to produce a better result (...) that would also keep up your motivation!" R: "Yes, it will."

The larger team appeared to be effective in gathering, integrating and applying knowledge, possibly because of the frequency and variety of interactions between its members, which generally meant they were able to complement each other. They asked each other for advice on problems with assessments or judgements, or when they found it difficult to deal with a patient or family. Moreover, it also struck us during the observation of the interaction pattern in the larger team that the formal hierarchy (the PEs are at the top, followed by the psychologist and finally the DNs - sometimes seniority or recognition of an expert status resulted in higher ranking in the hierarchy for someone otherwise lower down) was present in interactions, but it was rarely expressed in the form of members exerting dominance on the basis of their position or their personality. Most of the time, the team members approached each other as equals and showed appreciation for each other's expertise; contributions were assessed on the criterion of their value for the patient. The PE just as easily took advantage of the DN's expertise, for instance in relation to Ahmed who was not handling his sensor well and was afraid to prick at school: PE: "Can you make a schedule for him in which you mention how often he has to prick his finger? And perhaps explain at school, as well? And go through it with Ahmed in a quiet moment?" or, vice versa, in relation to Kees, who had offended the DN by bluntly refusing to attend an educational program: DN: "Can you find out why, and explain to him why we think it is really necessary?"

During the briefing for the annual check-up of Vicky, who was referred back to the PE by the internist after transition because she took irresponsible risks and refused to take advice, the team discusses the strict course that is to be followed. However, the DN who obviously knows the girl well, says: "You have to realize that she is already reluctant to come. Now, she has a new doctor, while she was really devoted to her former pediatrician. Let her just come with whatever she wants." This proposition is accepted; and as it turns out Vicky is very cooperative.

Disagreements and conflicts also occurred, for instance about the set-up of the weekly informal discussions. During the observation period, these sometimes led to confrontations, but not to a split within the team or to a loss of mutual trust.

Summary: Frequent, formal and informal interactions, complementarity and mutuality were characteristic features of the diabetes team. This facilitated the gathering, integrating and applying of (personal, contextual and biomedical) knowledge. Despite the formal hierarchy, we observed egalitarian relations and mutual appreciation among the team members. They gave each other advice and accepted each other's advice. They discussed disagreements and did not allow these to escalate into a conflict.

The infrastructure

The material infrastructure of the practice, which was partly built by the team itself, is well-developed. We will only address three elements; firstly, the *ICT facilities*. The constant availability of electronic information has become indispensable in the

care of diabetes patients. This infrastructural facility enables caregivers to communicate 24 hours per day; full patient details are available to all of them in real time and in easily accessible format. In addition, the electronic medical record shows laboratory results and diagrams that make the quality of the diabetes regulation, - the extent to which the biomedical standards are met - visible at a glance (stable or unstable; number of deviating values; the severity of the deviations; corrections applied; unexpected interventions). In this way, the ICT facilities support the integration of the different modes of patient knowledge. In this article we have chosen to include limited description of two other elements from the infrastructure: the *quality-of-life* questionnaire, which patients and parents complete separately at annual check-ups and which is discussed together, and the individual care plans which contain points of interest for the three months that follow.

The 'quality-of-life questionnaire' consists of 36 questions, distributed across a number of domains such as 'general', 'mood', 'body image', 'social life', and 'living with diabetes' and it also includes a couple of open questions. The introduction states that "the primary objective is (..) to identify possible problems and barriers (..) and to offer extra help where necessary." In an interview, one of the DNs explained what insights this list can provide: "Because of these lists, we gained more insight into the different aspects of the life of a family, without having to ask explicitly. Parents and child have the opportunity to introduce subjects for discussion themselves." Thus it helps the practitioners to obtain a better understanding of the impact the disease has on the patient's life. The first question has proven to be a good trigger to express themselves for adolescents who do not normally speak very easily about their illness and the concerns it causes them: "There is a ladder. The 10 at the top of the ladder means the best life you can imagine. The 0 at the bottom of the ladder means the worst life you can imagine. Where on the ladder is your life in general?"

Irma, who has an insulin pump, gives her life 7 out of 10. PE: "So, there's room for improvement, but it's not very bad either." I: "No, it isn't." PE: "What would you like to see changed?" I: "Er.." PE: "I had expected you would say 'no diabetes' straight away." I: "No, no pump." PE: "No pump? Why?" I: "I can't even wear a dress."

Jasmine, who also has an insulin pump, answers the question: "Does your diabetes prevent you from doing things away from your parents?" (parties, staying the night somewhere, going out) as follows: "I prefer it when they stay with me." The PE concludes from this that diabetes is causing undesirable social obstacles in this instance; she begins a conversation about removing these.

The personal care plans were developed by the team themselves. The plans are used by patients from 12 years on, and they are updated during each consultation. The patient's role is mentioned in the introduction: "You are responsible for your health yourself, together with your parents". Patients can specify the appointments they have during a three-month period; they read what they have to do before the check-up (test blood just before they go into the consultation, read out the pump one day before the appointment), and what they can expect during a check-up (discussion of blood test results, checking of pricked areas, weight, height and growth, questions about hyper and hypo attacks etc.). For every checkup, they can also write down what arrangements were made about the details

of the treatment: basal insulin, ratios, sensitiveness, target for blood glucose levels etc. There is space to address health objectives, but, above all, to set personal targets.

The personal care plan which the patient keeps up to date herself, has proven to be a rich source for the practitioners to acquire situational and personal patient knowledge. It illustrates what difficulties adolescents face in dealing with the illness. At the same time, the care plan stimulates reflection on dealing with diabetes in everyday life.

Summary: The three infrastructural issues mentioned have proven to be tools that patients can use to control their life with diabetes. For practitioners the tools can clarify a number of patient issues and concerns that would have remained hidden without them. Thus, the tools facilitate practitioners' integrating and applying personal, contextual and biomedical patient knowledge, as well as patients' involvement in these processes.

Second research question: How is (are judgements on) morally good care enacted in relation to the medical standards of the guidelines, and how are they expressed in ordinary actions within this practice? This question will similarly be addressed specifically for:

Individual practitioners

We observed that the PEs and the DNs in their contacts with patients regularly mentioned the medical standard that they were concentrating on: Optimal and stable regulation of diabetes to prevent early or late complications. It was also clear that they engaged with the patient on how that standard could be obtained in daily life. (For the latter, see the example of Tom, described under the first research question).

In the case of Judith, who has an insulin pump, and an HbA₁c value that is much too high (83) the PE finds out by asking questions that the girl only measures her blood sugars twice a day: in the mornings and in the evenings. The PE also finds out that Judith does not properly correct values that are too high. After many questions and negotiations they agree that Judith will measure at least four times a day, and that she will correct blood sugar levels that are too high. In this way she will try to reach the standard again.

However, during almost every consultation we also observed that practitioners pursued a moral standard (appreciating what is good for the patient as a person) even if this meant that they had to deviate from the medical standard, albeit within the confines of a certain bandwidth. Remarkably, the practitioners we observed seemed to take this as a matter of course. Although there were various differences, explicit deliberation about the principle appeared to be barely necessary. When asked about this, they explained it by: "It is all about the patient." "The patient must be able to carry on." The extent of the bandwidth within which deviations from the medical standards are deemed to be acceptable, was determined on an ad-hoc basis or in mutual consultation; and this bandwidth was not identical for every patient.

It transpires that Emiel, who has an insulin pump, has moved into his own place a few months before the consultation. This boy with a mild intellectual disability gets little support in dealing with his diabetes from his (divorced and also mentally disabled) parents (both of whom are living with new partners). He has accepted a job at a car wash and is running his own household: he does his own shopping, cooking and cleaning. He even

managed to decrease his HbA_1c value from 92 to 80. It is evident that he counts his carbohydrates fairly assiduously and adjusts his insulin dose accordingly. The PE and DN both consider this such a great achievement that they congratulate Emiel and motivate him to continue in this vein ("Keep it up! Good job!") without mentioning "but of course, the standard is 58."

Jasmine is over-accurate and worries about her high glucose levels. It transpires that her HbA₁c value has risen from 41 to 48. The PE tries to rein her in, judging that the strict regulation of blood sugar levels is threatening to dominate the girl's life; furthermore, she recognizes the risks for the future (becoming demotivated by the instabilities of adolescence that are irreversibly approaching). She says explicitly that she is very pleased with these levels and stimulates the girl to check her blood glucose levels less often.

Summary: The practitioners prioritized moral norms above biomedical standards and in fact did take this as a matter of course. They determined the limits of justifiable deviations from the biomedical standards through reflection and deliberation. The acceptable deviation bandwidth was different for every patient.

The diabetes team

It is striking that the psychologist on the team (whose discipline predisposes her to be less focused on pursuing exclusively biomedical norms), regularly and explicitly raised the question: "What is *good care* here?" This question usually was followed by a dialog during which various considerations were discussed and a direction was chosen. An example:

Alice is able to achieve with her insulin pump a sharp regulation of blood sugar values, but also has many hypo attacks which make her uncertain and ill-tempered. She is working as a trainee at a health care institution, with irregular working hours, including night shifts. The psychologist she is seeing due to severe family problems, proposes that she should stop with the insulin pump: "You have to look at the technical aspect (achieving balanced regulation) alongside the emotional aspect (being able to live a pleasant and quiet life) and you would like them to overlap. That doesn't always work." The PE and DN subsequently decide to switch to a schedule of four injections a day with an insulin pen, which does not permit the same accuracy in regulation, so that a rise of the average blood sugar level is expected.

Three months later, at the outpatient consultation (where she attends with her mother), Alice appears to be pleased and motivated and says: "I have a more pleasant life now." Her mother says: "We have chosen value of life; Alice is feeling better, she is more fun with higher blood sugar levels and it has become much quieter at night; she sleeps better."

Summary: in the diabetes team, the psychologist especially emphasized the priority of the moral norm over the biomedical standard. The team participated through mutual reflection and deliberation.

Facilitating through infrastructure

It is clear that the *electronic patient record* facilitates reflecting on the biomedical standard versus the moral norm. An unstable pattern and a lot of red figures in the laboratory results, pointing at deviations from the guideline standard, are, also, sure indications of a life that is frequently disturbed by diabetes.

The quality-of-life questionnaire constitutes a second resource: A low number on the list indicates that there is a problem with 'Living with the disease', often illustrated by answers to follow-up questions such as: "How often does diabetes stop you when you are planning to do something with the family?" and "how does diabetes hinder you in your social life, friend-ships and relationships?" or "how often does diabetes disturb your leisure time?" The answers give the practitioners valuable input for a conversation about achieving a balance between medical and moral standards. They can assist in weighting aspects: "What is most important for you?" and in looking for 'Livable' solutions.

The same is true for the *individual care plans*: The biomedical standards and the standards for the organization of care that have been incorporated in them. Under the heading: 'Health targets' the plan states: "Keep an account here of your (measured) values and living habits. Discuss what goes well and what could be better for you with your physician or with the diabetes nurse." This chapter of the care plan can provide starting points for an exchange and for the weighting of biomedical and moral standards in the consultation or in the team.

DN in team: "Alice may achieve a fasting blood sugar level of between four and six (that is the target), but that only works if she measures glucose (finger prick) during the night; it would interfere with her sleep. Maybe we should accept a higher morning glucose level." PE: "Yes, we should; a night's rest is very important for her. But how are we going to do that?"

Summary: the infrastructure creates scope for thinking together about a normal life, in which medical standards are judged in relation to moral norms. This was confirmed in the focus group.

Third research question: How is a balance established between agreed, appropriate goals for individual patients in their specific contexts, and the general goals laid down in the guidelines? This question is addressed specifically to

Individual care givers

Determining objectives, is a matter of defining purposes for the short term (motivation, tight regulation without disruptions, self-reliance or independence), and for the long term (absence of complications and a high quality of life in the long run). In their interactions with diabetes patients, the practitioners looked for acute disruptions, signals of poor motivation or poor acceptance of the disease, and of lasting dependency, in particular on parents, and subsequently discussed these.

Smart Joris, who has an insulin pump, is careless about his disease, and for instance only checks his blood sugar once or twice a day. As a consequence, he only narrowly escaped a major disruption on several occasions. The PE strictly confronts him with this behavior. Then Joris says: "I don't like my diabetes" PE: "You don't like your diabetes; you just don't want to live with it." J: "No, I don't." PE: "Right?." J: "Yes." PE: "Perhaps we have to start helping you a bit with it." J: "Yes." PE: "Cause that's the package deal: this diabetes belongs to you!" J: "Er.." PE: "and it won't go away if you don't stick to our plans." J: "No." PE: "Cause if you can control your diabetes well, there is a lot you can do. More than that: you can simply live a normal life."

Ilse, who also has an insulin pump, is going on a working holiday to Nicaragua. The pediatrician discusses the journey with her: necessary precautions; what she has to take with her, for in-

stance a spare pump and a spare meter, insulin pens etc. The pediatrician ends the conversation with: "You can consult directly with the diabetes team in the Netherlands about all your blood sugar problems. You can always contact us." The pediatrician judges, that precisely this patient, although she is very independent, needs confirmation that she can ask for help, if necessary.

For Emiel (see above), PE and DN see it as the maximum achievable result, that he is able to live an independent life (a job, a driving license, playing sports, performing housekeeping tasks, communicating, digitally about diabetes, and also, in case of illness or exceptional circumstances, keeping his blood sugar at an acceptable level within wider limits) and that this requires a major effort on his part. That is why they (possibly temporarily) accept his current blood sugar levels that are too high.

Summary: The practitioners interpreted the vague concept of 'Quality of life' as 'normal adolescent life among family and peers, with as little disruption or hindrance from diabetes as possible'. At the same time, they continuously were aware of the aim to prevent early and late complications for their patients. They had to deal with the tensions caused by the discrepancy between ideal and realizable goals.

The diabetes team.

Occasionally, sharing and exchanging knowledge about current developments led to high biomedical targets being adjusted.

At the briefing for the annual check-up, the intelligent, but quiet Roel is discussed. The psychologist shares her impression that Roel is being kept childish and dependent at home, because his parents are very concerned about disruptions. The team members agree without much discussion that Roel should become more independent and make arrangements on how to facilitate this.

The team probably realizes and accepts that promoting Roel's independence means at the same time that his diabetes regulation temporarily becomes less strict.

The team discusses Kees (parents recently divorced; he and his younger brother live alternatively with the father and the mother). All the practitioners see that it is very difficult for Kees that his parents argue a lot about how to deal with his diabetes. The father leaves (too?) much to the boy himself; the mother is over-concerned and even checks his blood sugar level with finger pricks in the middle of the night. The psychologist suggests that Kees is experiencing a conflict of loyalty and that he suffers from his parents' approach. However, loyal as he is to both parents, he does not want to discuss this burden with other people. This could also be the reason why he is refusing to attend educational meetings.

The team members agree on a short-term aim for Kees in this fragile context: to be able to sustain the situation without serious deregulations (so temporarily accepting higher blood sugar values) and to maintain his care relationships with the team (so temporarily accepting that he won't attend educational meetings).

Summary: the practitioners needed the discussions and the sharing of responsibilities in the team to be able to adjust the purposes set out in the guidelines, and thus to deal with the tensions mentioned above.

Facilitation by the infrastructure.

The purpose of the international guidelines has been incorporated explicitly into the *quality-of-life-questionnaires*, but it has been reduced to more modest proportions: "Help children/adolescents in their efforts to overcome psycho-social problems and barriers." The questions are specific; answers constitute the basis for discussing everyday life and impediments that patients experience, with the aim of removing them. One example is the objective: "I am satisfied with the way I look."

The individual care plan offers scope both for general purposes derived from the guidelines (the 'know' and 'can do' goals) and for personal objectives. It often mentions typical everyday challenges for the patient in question, such as:

"Think of something that can remind me to do blood sugar checks when I am playing at a friend's." "Think about at what age I want to be ready to go to an internist." "When I get the pump, measure my blood sugar at school as a fixed habit." "I am going to make an appointment at the hospital, together with my parents and my girl-friend to decide whether I want to continue with the pump."

It is clear from the preceding that, although the ideal purposes of the guidelines set the horizon for professional care, the practitioners and the team frequently opted to (possibly temporarily) adjust these purposes to what they thought was feasible, realistic or desirable for each individual.

Summary: the findings illustrate that this practice focuses on constantly gathering knowledge about the individual patient (and her perspective) in her situation, in addition to gathering biomedical patient knowledge, and to integrating these types of knowledge. We observed that with the help of the integrated knowledge the practitioners regularly considered to what extent it was possible to deviate safely from the biomedical standards on the basis of the moral standard: To live a good life with the disease. Purposes were broken down into feasible sub-objectives; the absolute ideal of the guidelines was regularly reduced to a realistic target: To carry on with daily life, with as few disruptions and restrictions on account of the diabetes as possible. Thus, a balance appeared to be struck regularly between the guidelines on the one hand, and the particulars of a patient in her specific context and situation on the other. We were able to describe how these balances were enacted, and we will reflect on this under 'Reflection'.

We asked the focus group about factors that they experienced as being a hindrance or a help when it came to this process of constantly balancing the guidelines with the specific situation of the individual patients. They mentioned two major impeding factors: 1) no or very limited professional relationship, for instance when they had to unexpectedly take over from a colleague. They stated that it was difficult or even impossible to build a relationship of trust under pressure. In these circumstances, they mostly made only medical-technical agreements with patients. 2) Time constraints, being in a hurry, stress through overburdening. The group emphasized that they needed a certain peace of mind and relaxation to be able to observe, judge, weight and decide properly. Although this has been taken into account in the planning of consultation hours, the schedule is often disrupted by unforeseen events. The practitioners mentioned three major supportive factors: 1) Mutual support in the team, mutual deliberations, joint training courses and working together to organize activities for patients. 2) Be-

ing able to discuss questions or problems instantaneously and informally with one or more team members. 3) Being familiar with the living environment of their patients and being able to give care 'close to home'.

However, the underlying question of this study is the question of the 'grammar' [33], or 'internal logic' [19,16] of the practice.

The 'Internal logic' of the practice

As stated above, we have tried to improve the abductive analysis, by using the lenses of relationality and practical wisdom. What did we see through these lenses?.

Relationality

The relationality lens enabled us to distinguish the 'Logic of the practice' in the *structure and content of the consultations:* from the beginning through the central part to the conclusion. *The start of consultations* appeared to be aimed at (re-) affirming a relationship, which can be characterized as open, confidential and safe. The practitioners did not go straight to the point; the greeting was always very cordial: The practitioner turned to the patient, looked them in the eye, shook their hand and welcomed them by saying "Hi, hello, Niels", or "Welcome, Irma", followed by an expectant "How are you?" This welcome was often followed by a few pleasantries: when 15-year-old Erik arrived, without his mother for the first time, he was greeted with: "Hey, Erik, all alone!!! Cool! Did you tell her to stay outside?" Now and then there was small talk or a direct question: "Did you pass your driving test?" or "How was Nicaragua?"

During the *central part*, the 'body' of the consultation, the subject was diabetes itself, recent incidents, the measurements presented, difficulties and questions, physical examination and the best possible approach for the period ahead. The characteristics of the relationship mentioned above probably made it easier for patients to express mistakes, difficulties that they experienced and concerns. Practitioners asked *direct questions*, asked further questions if necessary and listened intensely. It was striking in this context that they alternately adopted the professional perspective and the perspective of the patient's life. In addition, that they actively looked for the meaning-forthe-patient of any behavior or expression. Only when they had been able to discover that meaning, did they present their advice, and this in a way they judged to be suitable for the patient.

Lucas has a diabetes pump, is in the midst of puberty and is very focused on his appearance: he wants to look slim and muscular, and that is why he does not want to inject into his abdomen. His diabetes regulation is far less stable than it was in the past; he has been injecting extra insulin several times a day and despite this, his HbA₁c value has increased. When he is asked follow-up questions, he appears to assume that a larger insulin requirement means that his diabetes is 'Getting worse'. He is therefore unwilling to agree to a higher dose of basal insulin. When the pediatrician has managed to clarify this, she explains in detail that he has a greater insulin requirement, because " that is normal for your age, because the sensitivity for insulin changes, that is consistent with your growth, that is consistent with your build, that is consistent with puberty, isn't it, so, actually it's a normal phenomenon." In addition, the pediatrician cautiously suggests to Lucas that he should also consider injecting into his abdomen, but does not insist that he should start doing this immediately, because she expects that he needs time to adapt his behavior.

The fact that practitioners sometimes paid a relatively great deal of attention to professionally insignificant matters (which, however, were obviously bothering the patient, even though they were unrelated to their diabetes), seemed to result from their habit of listening intensely and inquiring actively into the patient's concerns.

Emiel (see above) is concerned about pimples on his legs. The pediatrician spends much time talking about this, examines his legs thoroughly and discovers a connection with Emiel's work at the car wash. He explains that it is probably a harmless rash, and that Emiel can probably solve the problem by applying Vaseline to the affected areas every day.

The conclusion of a consultation included making or summarizing arrangements for the next three months period. The way this was done varied however: from going over everything very explicitly and item by item to simply mentioning everything in passing, or even a general 'carry on'. It is evident that the practitioners adjusted the way they approached the patient to what they believed was necessary or appropriate in the professional relationship: sternly, encouragingly, stimulatingly, casually, etc. Goodbyes to mark the end of the meeting were usually warm and informal: "See you soon." "Happy holiday." "Good luck with your test."

Our observations show that the absence of relationality on several occasions, caused problems (mutual misunderstanding, conflicts) or awkward conversations, particularly when the subject under discussion was a lack of compliance or an unstable diabetes regulation:

Ahmed, who has been living in the Netherlands for a few years, visits the consultation with his parents. They are refugees from the Middle East. Ahmed has an insulin pump and a glucose sensor, but he uses these devices in a manner that increases risks. The DN has asked the new PE, who is going to have her first encounter with the patient, to discuss this problem with him. The PE agrees to do this. At the start of the consultation, she is nervous and she immediately raises the problem: too few calibrations of the sensor, insufficient corrections of high glucose levels and too high HbA_1c values. A conflictual situation then arises with the father, who even accuses the PE of discrimination.

Afterwards, reflecting on the case, the PE suggested it would have been better not to have accepted the DN's 'Order', precisely because she had not yet been able to build a relationship with the patient and his relatives.

Professional relationality has to be built and maintained; it is a specific kind of relationality that is needed to attune care every moment anew to particular patients in their specific situations. For mutual relationality it is also essential for patients to believe, that practitioners' aim is to achieve the best possible outcome for them, so that they are willing to be honest and open.

Our study shows that the practitioners and the diabetes team focus their 'Ordinary actions' on entering into and maintaining a professional relationship with patients and their relatives, as well as on accepting their professional responsibility in these relationships. In addition, that they succeeded in using that relationship to acquire and renew the personal and situational knowledge they need in order to fine-tune their treatment of the diabetes patients. One of the pediatricians in the focus group pointed out: "You always have to keep working on

the fragile relationship with the patient based on mutual trust. That is because the patients must be able to rely on you any time they need you." In conclusion, this study proposes that relationality as described belongs to the 'grammar' of professional care. The other important constituent appears to be practical wisdom, to which we turn now.

Practical wisdom

Practical wisdom emerged preeminently as the ability to determine, sometimes in an instant, what is good for the patient, what the patient needs to continue her life. In addition, it appeared as the ability to individualize medical standards and the objectives of the guidelines.

Our observations give rise to further elaboration on how individualization was realized in this practice. In the first place, it involved estimating the bandwidth within which it was possible to deviate from the medical norms without harmful consequences for the patient, and it involved determining the bandwidth margins. The ability to judge was essential for the practitioners and the team to be able to perform this task. For instance in the case of Emiel, the team members judged that, unlike the former value (92), an HbA₃c value of 80 was acceptable for that particular moment. The DN confirmed in an interview that she expected Emiel would soon learn to approximate the threshold. Thus, the judgement above, like other judgements appeared to be influenced by the situation, by the here and now. Individualization was also evident in judging the hierarchy of norms, in which moral norms were sometimes put alongside and sometimes above medical norms.

In the case of Emiel, the practitioners judged that (in the current situation) it was more important to help him lead an independent and meaningful life, than to hold him to the optimal HbA₁c value. In the case of Alice, it was more important to reduce stress levels caused by the disease, to improve sleep, and to achieve greater stability than to recommend use of the insulin pump according to the guidelines. In the case of Kees, it was about being able to survive the conflict of loyalty with his parents rather than being forced to attend educational meetings.

At the same time, however, the practitioners know that if they allow patients to free themselves of the standard, there could be harmful consequences due to early (acute disruptions) or late (vascular damage) complications. Practical wisdom emerges in the ability to compromise between skirting the norm and crossing critical limits.

Likewise, adapting the excellent objectives of the guidelines to objectives that are regarded as feasible for a specific individual: a life that patients can bear because they do not experience it as a disabled life, appears to be a manifestation of practical wisdom. The practitioners kept looking for the best possible 'overlap' between the ideal objectives and their patients' personal objectives. To this end, they used acquired knowledge of the person and their situation, such as impairments patients were already living with (Niels' autism, Emiel's intellectual disability, Vicky's psychological lability, conflictual living conditions (Kees), and lack of understanding in the living environment of school and work (a ban on checking blood sugar during class time).

At the same time, practitioners were serious about the prevention of early and late complications, focusing on a life-not-disturbed-by-the-disease in the future.

PEs emphasized this during the physical examination: "Always prick the side of your fingers and switch fingers regularly. Why is this again?" They promoted developing a life style that includes sports and exercise, gave extra attention to the regulation of blood sugar when engaging in physical exertion and sports, and they did this both individually and during educational meetings. They also highlighted the prevention of complications during their discussion of the insulin-pump read-out and the blood sugar diagrams: "What can the results be if your blood glucose levels are too high or too low?" followed by: "What can you do to prevent these highs and lows?' And when giving individual advice: Emiel is told by the DN: 'Now that you are living on your own, ... when you go to sleep after an evening out, you have to set the alarm clock to measure your glucose level." The PE tells Joris: "It's dangerous to deal so carelessly with your pump; perhaps you'll have to go back to using the pen."

We observed an ongoing search for the best possible way to follow, meandering and improvising, supported by inventiveness, intuition, tacit knowledge, and experience. The professionals in the focus group acknowledged that this was essential to their craftsmanship.

Doing relationality and practical wisdom

Our observations show that relationality and practical wisdom are established in the doings and sayings of the practitioners and the team and in addition, that these must be reestablished in every new situation (a new problem, a different check-up appointment). They also demonstrate that relationality and practical wisdom occasionally failed to help a patient well, despite the practitioners' efforts and deliberations. For instance, it proved impossible to support Kees in his loyalty conflict with his parents. Over time, he switched hospitals, owing to the imminent obligation to attend the educational meetings.

We also observed that relationality and practical wisdom were *imbedded in self-developed, routinized actions, within the team and the infrastructure*: Consultations that begin by asking questions to establish the context; structural discussions before and after the consultation; sustained sharing of knowledge; the team culture and a way of cooperating that was aimed at complementarity and reciprocity and the desire to bear responsibility together; discussing care plans and quality-of-life-questionnaires with patients.

Finally, we saw relationality and practical wisdom emerge in the quality of the professional attitude adopted by the practitioners: Searching for solutions together with the patient; looking for and responding to concerns; discussing possibly tolerating a deviation. We also occasionally observed it when the practitioners adopted a specifically teaching, educational attitude to transfer their expertise, attuned to the individual patients, in suitable doses and in a dialog with the patient. And also, whenever the practitioners in question approached the patient as an expert on her own disease. Sometimes they were surprised by solutions that patients or relatives had found.

Lucas' mother found a special needle on the internet that can be used to install an infusion system, so that insertion is less painful. Jeroen's mother proposed that she would measure her son's blood glucose levels and adapt his insulin pump after an operation her son had to undergo, when the anesthetist admitted she found it difficult to do this.

Summary: the 'internal logic' or 'grammar' of this adolescent diabetes practice is characterized by relationality and prac-

tical wisdom. Relationality and practical wisdom appear to be indispensable to enact accurate balances between personal-situational and guideline knowledge, norms and purposes.

Reflection

Our research questions were aimed at *the enactment* of workable ratios of guideline knowledge, standards and goals on the one hand and patient oriented knowledge, norms and goals on the other, in an outpatient diabetes practice. We have described the outcomes of the study per question in the results section. Apparently, ordinary actions have to be attuned time and again to each patient in a purposeful, continuous and multifaceted way in ever changing situations. Hinder and Greenhalgh [44] have emphasized the importance of personal and situational knowledge in caring for people with a chronic condition. However, they did not point out in what way this knowledge can be properly balanced with guideline knowledge and standards from moment to moment, in everyday practices.

In addition, we found that the underlying 'Internal logic' of the practice was characterized by *relationality* and *practical wisdom*, and we have described *how* relationality and practical wisdom were established. So far, hardly any attention has been paid to the empirically investigated 'How' and the 'Internal logic' of medical practices in publications, with some exceptions: [19,34,17,15,16,35]. The results section shows that our empirical findings differ from statements about relationality and practical wisdom in theoretical publications.

For example: professional relationality turns out to differ significantly from simply having empathy, or from communicating excellently, as Bensing [57] and Visser [58] seem to believe. Conversely, professional relationality as a practice means the enactment of knowing and understanding a contextualized patient and her perspective. This study demonstrates additionally, that it means the imbedding of relationality in individual practitioners', team and infrastructural routines, culture and structures, for example in structural team discussions before and after each consultation, and in a culture of confidentiality and safety. The performativity of cultural aspects in practices has been confirmed in an empirical study by Setchell et al. [28]. The embedding of individual activities in the actions and influences of other agents (like team, culture and infrastructure) has also been described as a necessary condition for the emergence of practical wisdom defined as acting virtuously within organizations by Vriens et al. [29].

Although the ability to individualize has been mentioned as an essential element of practical wisdom by Aristotle and other autors [59,4,6,7,38], none of these authors has further elaborated on how individualization is realized in practices. We have found that it involves estimating the bandwidth within which deviating from medical standards is judged acceptable, and that it involves determining bandwidth margins. This again has been demonstrated in other *empirical* studies of practices. For example, Mesman [34, p. 159] has called the process that concerns the demarcation of boundaries a "source of morality in practices." Saraga et al. [35, p. 44] have mentioned "trespassing common boundaries and limits" such as guidelines "by applying one's own judgement or intuition" as a characteristic of clinical practices.

Kaldjian [5,6]; and Pellegrino and Thomasma [10] have emphasized goal-directedness as a feature of practical wisdom, but they did not pay any attention to the practical challenge

of bridging the gap between excellent and realizable goals. The empirical investigation of Franklin et al. [21] have illustrated that health professionals' interaction styles determine to what extent patients' participation on personal goal setting is allowed. Our study has clarified that even practitioners' interaction styles must be attuned to the particularities of patients and their actual situation.

Kinsella [14] has called the art of balancing a characteristic of professionality and practical wisdom. Kaldjian [6] and Montgomery [8] have mentioned sound judgement an identifier of practical wisdom. However, none of them was able to explain that balancing and judging are being established by an ongoing search for the best possible way to follow: Meandering and improvising, supported by inventiveness, intuition, tacit knowledge, and experience. Conversely, the observations of this practice as well as discussing everyday work with practitioners revealed, that professionals judged these features to be essential for their craftsmanship. Mol and Law [15], describing ethnographic observations of practices of care, have used 'Tinkering' to characterize the improvising, meandering working method of practitioners.

Finally, the problem of *uncertainty*, that is currently inextricably linked to professional practices [60], has differently been addressed from within practices. In the focus group, the professionals involved indicated that they experience deviating from the biomedical standards and the goals of the guidelines as a continuous and burdensome uncertainty which is inextricably linked to their life as a professional. 'Is it possible always to comply with the guidelines? At what cost? How do I know that I am right? Nobody can take that uncertainty away from you.' Mesman [34, p. 159] has contended in relation to this: "That the existing rules carry a certain idea of a practice and a problem and that this does not always fit with real practices." This study has revealed that deliberations in a committed team can be very important in supporting practitioners, who have to endure these uncertainties.

The relevance of this research emerges in the fact, that over a longer period of time we have observed the everyday practice of taking care of patients suffering from a chronic disease, through the lenses of relationality and practical wisdom. Although care ethicists have pointed out that relationality is essential for people to live together in this world [61,62], and practical wisdom has been identified as necessary for medical professional practices [6,7], so far, relationality and practical wisdom have been described mainly theoretically from the outside, and mainly as characteristics of individuals. This case study shows from within a medical practice, in what way relationality and practical wisdom are enacted. This has not been done before in such an extensive and longitudinal way.

Limitations

Although they were extensive, our observations only covered a limited section of the diabetes practice: limited in time – developments go on; for instance the diabetes practice of the hospital concerned has in the meantime been transferred to a larger hospital – and in the elements they focused on. For example: The professionals in the focus group indicated that the practice as described was the result of a lengthy and fragile growth process, that included trial and error. Our study was not, however, designed to give any attention to this growth process. Nor could it reflect on the wider organizational and national infrastructure of the practice, even though there is so much more

to say, for instance, about the influence of technologies on life with and treatment of diabetes.

The lenses we have chosen form a second limitation; they show a number of aspects of the practice sharply and clearly; but other elements remain vague. Observation using other frameworks would certainly have highlighted other aspects. For instance, it has been insufficiently clarified that treating patients with a chronic disease is an ongoing process, not the sum of isolated moments, and that the examples in time, place and persons that are depicted are only incomplete representations of that process, as Schermer [20] has emphasized too.

A third limitation arises from the case study as such. As Anderson et al. (2005) have described, case studies make it possible to study a practice as an integrated whole, but at the same time it is difficult to generalize from them. That is why our aim instead has been communicative generalizability or 'transferability' [63, 41]. This means that the readers must judge to what extent the results can be transferred to their own practice.

Conclusion

Care given in this practice was good care to the extent that it was possible to stay close to the patient, to move at the pace of the patient's difficulties and concerns and at the same time, to comply with medical evidence, norms, and purposes in the best possible way. A certain synthesis was often, but not always reached through the 'Logic' or 'Grammar' of the practice, which consisted of relationality and practical wisdom. The thorough empirical investigation from within this everyday practice has enabled us to describe the characteristics of this grammar.

We also conclude that in modern practices, individual professional acting is embedded in the social and material network of the practice: in the treatment teams and the infrastructure (in a narrower and a broader sense). This means, that relationality and practical wisdom do not only emerge in the actions of individuals, but also in the social and material agents which together constitute networks. Our study has been able to demonstrate this in the practice in question through numerous examples.

Future research could focus on further exploration of these networks and the influences that are brought to bear upon them, in particular, social and material influences, as well as on the broader infrastructure of practices, constituted by health-care organizations and the funding and supervisory bodies that surround them.

Notes

- 1. International Society for Pediatric and Adolescent Diabetes: ISPAD Clinical Practice Consensus Guidelines 2018. https://www.ispad.org/ISPADGuidelines2018
- 2. Standards of Medical Care in Diabetes 2018; American Diabetes Association. In: Diabetes Care (41) (Supplement1): S1-S2. https://doi.org/10.2337/dc18-SINT01
- 3. NDF Zorgstandaard; Addendum Diabetes type 1; Deel 2 Kinderen en Adolescenten. [DDF Standard of Care; Addendum Diabetes type 1; Part 2 Children and Adolescents]. 2009. Nederlandse Diabetes Federatie [Dutch Diabetes Federation]. https://www.diabetesfederatie.nl

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