

A number in circulation

HbA_{1c} as standardized knowledge in diabetes care

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A glycosylated haemoglobin test, HbA_{1c}, is a blood test that measures how much sugar is bound to the red blood cells, or haemoglobin (Hb). Since red blood cells break down after about 120 days and new ones are formed, HbA_{1c} can be used to check the average blood sugar over the last two to three months, and thus how a patient is managing their diabetes. If the patient's blood sugar levels have been good, less sugar will be attached to the haemoglobin. On 1 September 2010, HbA_{1c} tests in Sweden were changed from being given as a percentage to being given in mmol/mol. As a result, patients' HbA_{1c} results became comparable, not only individually, but also across cohorts of patients, and as an average value for regions and the entire country. It even became internationally comparable between countries. In other words, HbA_{1c} tests circulated on an entirely new scale and took on various meanings in relation to the diagnosis of diabetes. In this chapter, HbA_{1c} is investigated as a form of standardized knowledge in diabetes care and the significance this form of knowledge has for a variety of practices is explored. HbA_{1c} is discussed here as a value expressed in figures, but where the figures are interpreted, translated, and understood—enacted—in different ways, depending on the practice presenting or using the figures. Ethnographic methods allow us to follow the figures and how they are discussed,

whether at staff meetings or in individual clinical encounters with parents whose children have recently been diagnosed with diabetes. These are figures which can serve as a key metric in the narrative that professionals create in the clinical encounter, a narrative that emphasizes the importance of managing one's diabetes (Arduser 2017). It can also be a narrative that visualizes developments at an endocrinology department in a national comparison with other departments' averages for HbA_{1c}. However, the representation of figures produced by HbA_{1c} testing is not limited to narratives or visualizations, but is used for a wide range of quantifications, measurements, and standardizations according to the subject—doctor, nurse, patient, parent, and so on (see Larsen & Røyrvik 2017). In other words, it forms the normative guidelines to which various subjects relate differently—it is a conditional circulation.

This chapter explores how figures are used in medicine to create normative guidelines, and how figures are variously interpreted and used depending on the contextual practice. I begin by presenting HbA_{1c} and the study's methods and implementation, and then trace the figures from the clinical encounters to staff meetings, all in a Swedish welfare context.¹ Clinical encounters establish the significance of the figures for the interaction of medical staff and children with diabetes and their families. This practice is then compared to how the professionals discuss and use HbA_{1c} at staff meetings, and how this relates to a national context, which sees medical professionals use the figures to compare themselves with other endocrinology departments. The chapter concludes by addressing not only how HbA_{1c} creates figures which are in constant circulation, but also by examining the subjectification processes in which the individual becomes 'diabetic' by the use of these figures and others (see Agamben 2014). In the next section I begin the chapter by addressing the question of the realities where these specific figures—these dispositifs—apply.

The all-important figure of 52

A *dispositif* is a theoretical concept that renders visible the relations that arise when a harmless object such as HbA_{1c} is put into practice, creating a network of power relations between, say, a medical institution and the individual (see Agamben 2014). It is in the meeting of individual and *dispositif*—here, HbA_{1c}—that the subject proclaims itself, be they doctor, nurse, patient, or relative. This assertion was something I saw in one of the many staff meetings I attended which brought together all the department's specialists to discuss, on this occasion, a leaflet about HbA_{1c} for families whose children have diabetes. There were nearly twenty people seated at a long table, mainly doctors and nurses, but also dieticians, counsellors, psychologists, and medical secretaries, who together made up the hospital's diabetes team. Most of them fetched mugs of coffee or tea, and, having agreed on the agenda, began by discussing the leaflet.

One of the key points in the leaflet was that 'Your diabetes treatment goal' was an HbA_{1c} of 52 mmol/mol.² This was a test done when the patient attended the hospital clinic; it was not something the child or their family could measure on their own.³ To achieve this goal, the diabetic child had to keep their blood sugar at a low level. The leaflet therefore spelt out these levels, with, for example, 'Blood sugar before a meal: 4–6 mmol/l' and 'Target value at bedtime 5–7 mmol/l'.⁴ If the family arranged everyday life practices so the child's blood sugar remained within these averages, then the chances of achieving the HbA_{1c} target of 52 mmol/mol increased. In order to achieve this the leaflet had a section with 'Help reaching your goals', which began with 'Test your blood sugar before every meal!' followed by 'Hypoglycaemia', 'Correction dose', 'Counting carbs', and 'Exercise'. These points summed up the hope that the family would take responsibility not only for the child's treatment, but also for reaching their health goals with a form of self-care (Alftberg & Hansson 2012; Arduser 2017; Liu and Lundin in this volume).

What was this self-care that the parents or patient were expected

to manage? *Hypoglycaemia* is when blood sugar falls below 3.5–4 mmol/l, which the individual should treat with glucose to raise their blood sugar. If their blood sugar is above 8 mmol/l then they need to take a *correction dose* of insulin, and their blood sugar should be checked again after two hours. Family and teenage patients should learn to *count carbs*, adjusting the insulin dose according to how many carbohydrates there are in the meal the patient will eat and what physical activity is planned afterwards. By looking at both, the family can ‘estimate how much insulin is needed for a certain quantity of carbohydrates’. It is thus not a question of there being a fixed dose of insulin to take, but rather a form of self-care in which the family calculates the correct dose of insulin. When it comes to *exercise*, the leaflet pointed out that ‘Physical activity will help you reach your goal. Regular exercise will help keep your blood sugar stable and you will feel better in both the short and the long term!’ This information imposes a dispositif on the family that not only creates a relation to the ‘standardized knowledge’ of healthcare (Agamben 2014), but also makes visible the knowledge subject who has experience enough to practise self-care (Foucault 1978; Alftberg & Hansson 2012).

At the staff meeting, the first person to talk about the leaflet was one of the doctors, Emma, who wanted to stress it was very useful, because it gave the family information about HbA_{1c} and because ‘patients are happier for taking something with them’ when leaving the clinic (meaning that most families of children with newly diagnosed diabetes liked having both verbal and written information). One of the other doctors, Anders, objected, noting that ‘At the same time they get the diabetes book, and that says that you should not obsess about HbA_{1c}’. Emma believed that the perspective in the diabetes book was incorrect, and she had a different experience from her clinical encounters, namely that the need for information about HbA_{1c} varied from family to family: ‘Good to have it on paper, but it’s individual.’ By way of example, she talked about a family where the parents had separated and ‘don’t know which way they’re facing’: for them, the target values

in the leaflet were a help. The goals were something the parents could agree on, and set the tone in both households for how the two should manage their child's diabetes. Kerstin, one of the older doctors, pointed out that HbA_{1c} risked 'being judge and jury' for families who, not as successful at managing their child's disease, had readings well above the target value of 52 mmol/mol. Many around the table wanted to comment on this—plainly, Kerstin's statement was the sort that elicited differing opinions. Some said there was a risk of creating 'neurotic parents and patients' because of all the endless calculations they would have to do to reach an HbA_{1c} of 52 or below. Emma defended her position, once again referring to the families who were happy with the information by saying that 'many people think it's comforting'. Kerstin qualified her earlier statement by saying it was important that they 'never hand out the document without saying how it should be used', and finished by saying 'one must discuss it'.

This ethnographic description of how the leaflet was discussed by medical professionals shows that HbA_{1c} is not value-neutral. Instead, it comes down to a figure linked to medical treatment guidelines, which are understood and interpreted according to the practices of the healthcare professionals at the staff meeting. The medical staff fell into at least two camps. One welcomed parents and children being given information about how they should manage their treatment in their everyday lives to reach an HbA_{1c} of 52 mmol/mol. They pointed out that parents and older children could aim for this with regular blood sugar monitoring, counting carbohydrates before taking insulin, and encouraging exercise. Under those circumstances the HbA_{1c} test taken when the family attended the hospital clinic would not be an abstract value, but rather could be an acknowledgment that the family had successfully treated the child's diabetes on a daily basis. Given this, we can better understand Emma's statement that 'it's comforting' for parents to know about the target value and that it is worth trying to reach it. The professionals who objected to the leaflet felt that the focus on figures, insulin doses, carbohydrates, and exercise meant

that the illness featured too prominently in family life. This is not immediately evident from this ethnographic description, but it was an enduring topic of discussion at staff meetings where the health-care professionals looked at diabetes care. There were parents and patients, they said, who overdid the counting and became 'neurotic', forgetting to carry on living their lives as before the diagnosis.⁵ The attitude was that today's advanced diabetes treatment should not only reduce the long-term sequelae, but can also enable families to continue living much as before. Some felt that an HbA_{1c} of 52 mmol/mol could be felt by families and children to be casting blame, instead of encouraging them to work with medical staff to become better at managing the disease.

A central feature of the discussion was how the medical professionals used the figure of 52 in certain ways to argue for their views of diabetes care. The figure thus took on different meanings. Was it a figure parents and patients should strive to attain, or was it a figure that should be hidden away and not talked about in clinical encounters? Was it only of relevance to medical staff, or should families and children be told it was a target value? There is no easy answer to these questions; as we will see, the different uses are reliant on the data to accord to the practice. At the staff meeting, the figure was an opportunity for individuals to position themselves on how they as professionals related to the treatment of diabetes. The figure was not simply a figure, but also a naming practice that made the world intelligible to the professionals (Eliassen 2008). The professionals could talk about the parents and patients as those who reached the target and those who failed and thus needed more help from the healthcare system. There was the latitude to include in this the 'neurotic' families who were too controlling of their children. Whose attempts to manage the disease had an adverse effect on family life, and similarly to reflect on the clinical encounter and that some patients and families felt the figure was 'judge and jury' on whether they had taken responsibility for their child's self-care. The figure allowed them to pigeonhole families and patients they met in clinical encounters into what amounted to a naming practice.

Gunhild Tøndel argues there are two naming processes, where the one seen here is to use figures to name and identify *things* (2017). HbA1c enables medical staff to identify patients, in the same way that patients and their families can relate to it as a value—a form of subjectification process (Agamben 2014). In the second of Tøndel's naming processes it gives each patient an identity, and can thus follow their development using the figure. Here the name is a tool that enables social and material organization (Tøndel 2017). By taking an HbA1c test every time the patient attends the clinic, it becomes possible to monitor each patient's progress. This is a form of the desubjectification process: it is nearly impossible for the family and the patient to avoid the dispositif, and instead they are subject to HbA1c's specific way of ordering reality (Agamben 2014).

The HbA1c test thus generates categorizations, embodied in figures that differentiate between values—values thought of as good for patient health versus values thought to have a negative impact on patient health. The categorizations are also central to the interaction between the subject and the figures (Hacking 1999). In the ethnography above, this interaction took the form of positioning, as the various professions—the doctors primarily—chose how to relate to the blood test, which resulted not only in their differing approaches to HbA1c, but also in that interaction being placed front and centre in the clinical encounter. The categories impact how the subject perceives and acts in daily life—in the lifeworld (Husserl 2002)—but at the same time they serve as exclusionary mechanisms by ensuring that one interaction takes place but not another, so creating standardized knowledge which, depending on the practice, has a claim to power (Foucault 1993).⁶ As described in the ethnography above, it was the doctors who positioned themselves most strongly and used their standardized medical knowledge of HbA1c to express their views on the best diabetes care, which came down to a choice between providing families and patients with a great deal of information or limiting it somewhat. We can thus follow HbA1c as a test of a range of practices, charting how standardized knowledge generated by the figures takes on different

meanings according to how those figures are used. One central practice in healthcare is the clinical encounter, but before studying how HbA_{1c} is mediated and negotiated—or used, I will turn to the study's methods and materials.

Follow the numbers

Ethnographic descriptions have been used to follow medical *things* in a variety of practices (Prout 1996; Whyte et al. 2002). In the present study HbA_{1c} is just such a thing, which we can follow and describe as it is produced, used, and transformed in different situations. These descriptions use a wide range of ethnographic methods, and generate a multifaceted material with which to capture the full complexity of HbA_{1c} (Marcus 1995). The study is largely based on observations, but such methods as observation-based conversations and document analysis were also used.

Ethnographic observations require the researcher to be present in the setting to be studied, and to record the specific context by describing in words the course of events and settings. An example of this kind of ethnographic description is given above. It is by the researcher's presence it becomes possible to not only describe how figures are presented and discussed, but also how they are used, interpreted, rejected, problematized, promoted, or ignored. Frequently this is hard to capture, because those involved do not necessarily reflect on the process or because it happens unconsciously; being present, observing, gives the ethnographer a greater chance to observe, which is not always possible with interviews or questionnaires (Frykman & Gilje 2003; Ehn & Löfgren 2010). It is central to the method that the researcher is present on different occasions, in order to then compare and problematize the observations. In this study, this comparative perspective is used to analyse how figures circulated and acquired different meanings depending on the practice.

Presence is a particular feature of the ethnographic method, and results in a unique empirical material that would not have

been possible if the researcher had not been present, observing. The corollary is that the material is coloured by the researcher's gaze and powers of observation. In this chapter, this is evident in occasional moments of self-reflection when the researcher's position becomes visible (Beckman 2009). This positioning is crucial in order to identify the circumstances of the observation and subsequent analysis. While this empiricism may appear subjective, the unique source material is invaluable for highlighting and problematizing cultural processes which are non-standard in medical and health-care research (Skott 2013).

Five staff meetings, similar to the one described in the passage above, were observed in the space of eight months. Some meetings were quite brief—over in an hour and a half—while others were longer and took a whole morning or afternoon. As the researcher I sat at the table, but to one side, and I avoided joining in the conversation. The professionals' conversations and actions were observed and written down in a notebook, and immediately after each observation the notes were assembled in a digital observation text about ten pages long. I also attached the documents that the group's professionals had produced or discussed on that occasion, whether the medical staff's working papers or information leaflets for patients and parents. Before and after the meetings I chatted with the staff, thus forming relationships that coloured my impression of them as individuals and as a group. Some of them I came to know in their professional roles, and in that way they became key informants, helping me understand the healthcare system better.

Another class of source material is the clinical encounter. For the present study I followed seven families, all with children recently diagnosed with diabetes, who had therefore been admitted to hospital on a fairly urgent basis. Treatment had fallen to the parents almost immediately—with the child participating if in late teenage years—and after a few days they could return home, initially on day release, but soon sleeping at home. After a week or so, the patient was discharged, but with a referral to the hospital clinic for follow-up care and regular check-ups. In most cases, as researcher I

entered the picture a few days after their first emergency admission to hospital, and I followed the family for three or four weeks. I was present for a number of their clinical encounters, seated quietly in the background, recording the conversation and associated events. The resultant observation notes formed the basis of the observation texts. These varied in length because the number of observations was different for each family; they range from ten to twenty pages of computer-written text. For each clinical encounter, I always arrived with the medical staff in the hospital department where the family were waiting. In the clinic, I rarely spoke to families in the waiting room, and instead remained with the doctor or the nurse. I deliberately avoided striking up a social relationship with the families or their children, having chosen this approach to my informants because the study is primarily focused on the healthcare professionals' daily lives, not on parents' or children's experiences of diabetes care.

The study was approved in advance by an ethical board, and besides complying with the principles of research ethics the fieldwork was discussed at length with colleagues during the project. This is a sensitive area of study, and the researcher must always consider the special situations that can arise when people meet in healthcare settings such as clinical encounters. It is not enough in an ethnographic study to conduct an ethical review; the researcher must maintain an ethical approach throughout, endeavouring to see the individual—the subject—and understand their situation (Hansson 2013; Fioretos et al. 2013). If nothing else, this approach lends itself to fieldwork, where researchers must be quick to adapt to any situation. This was also the reason I chose to follow the medical staff, leaving it to them to be the first to meet the patient and the family, and why I was always careful to be in the background in clinical encounters. All those involved have been anonymized for this chapter, and any identifiable personal characteristics removed.

Figures in clinical encounters

When Annemarie Mol (2002) followed hospital cases of atherosclerosis to study how bodies with the disease are not just specific actors as described in, for example, patient information, she found instead there were a variety of explanations when the diagnosis and the diseased body met in the clinical encounter, when doctors spoke at conferences, when testing and diagnosing patients, and so on. To capture this complexity, she suggests the concept of *the body multiple*; a very useful approach to understanding how different bodies are created by the healthcare system, depending on the practice. The term does not necessarily equate with a fragmentation of healthcare or a life with a disease, but rather that varying practices arise depending on the situation where diagnosis, body, and disease become visible, as something for all actors to relate to.

Much of the bodies' visibility is achieved with the figures found in the healthcare system's many practices. The figures are co-creators of the bodies that materialize when the patient undergoes the tests to generate data with which to make diagnoses and prognoses (Gadamer 1996). The patient's body could be one with good test values—good figures—and thus the individual or family is praised by the staff for managing their treatment properly. It might be that they show the patient's health is failing, whereupon another type of body results, one which must be corrected. The figures thus have the character of things that can either disregard the body or bring it sharply into focus when the figures bode ill (Heidegger 2013; Agamben 2014).⁷ The following ethnographic examples from one clinical encounter demonstrate this interaction, and how a single consultation can feature the body multiple.

The clinical encounter in question was a consultation with a doctor and a nurse at a diabetes clinic by a mother and father and their 4-year-old son. The boy had been diagnosed with diabetes a few weeks before, and the family had recently returned home and were now trying to fit diabetes treatment into their normal lives. The boy had gone back to preschool, but his mother was at home

with him the rest of the time. The consultation began with the nurse showing them how to download the blood sugar data from the boy's glucometer, which stores the readings taken by the family. The computer for this was out in the waiting room, and in future the staff expected them to do the download on their own before the doctor saw them, but the parents had yet to learn because it was their first time at the clinic since their son had been admitted to hospital. After the data was transferred, the nurse took the boy and his parents to a test room to do an HbA_{1c} test. The nurse turned to the parents to say, 'He'll have a lower HbA_{1c} than when he came in sick.' By stressing that the diagnosis had a before and an after, the nurse implied there were two bodies even before she did the test: when the parents took the boy to hospital there was the sick body that needed urgent care, and now after a few weeks of treatment here was this body, with its more stable blood sugar levels. This distinction was to recur in the clinical encounter, it being fundamental to this disease, because the patient will always have diabetes and so will always have to manage the treatment.

The parents did not comment on the nurse's remark, and instead the mother asked a question that seemed to be on her mind: at what point should they, the parents, check whether the boy has ketones. The nurse began by explaining what ketones are—the product of the breakdown of fatty acids, a substance the body forms when there is a lack of insulin or if the patient has taken too little insulin. Too many ketones will make a patient ill, and so-called ketone poisoning is life-threatening. To answer the mother's question, she added that they could 'try checking some time with a pee stick.' The mother wondered 'How?' and the nurse explained how to do it by holding the stick under the stream of urine for a second—but 'don't dip it into pee'. She also pointed out how important it was to do the test whenever the boy had an upset stomach or was vomiting to rule out ketone poisoning, because the symptoms are the same. After this exchange there was suddenly another body in the test room, a body which could become acutely ill, requiring the parents to act quickly and drive the child to A & E.

Suddenly, the machine measuring the HbA_{1c} beeped, and the nurse said '55' aloud so the parents could hear. The mother said immediately, 'But that's not 52.' The nurse responded by saying, 'But on the right track.' Previous consultations when they were staying on the ward, together with the paperwork they had been given by the staff, had impressed on the family they needed to get the boy's HbA_{1c} down to 52 mmol/mol, so it was not surprising that the mother reacted as she did: 55 was a value she felt was a failure. Yet as the nurse pointed out, it takes time for the level to fall from a pre-diagnosis high. The mother initially did not see things that way, and the figure of 55 attached itself to the boy's body as if he were still sick. The nurse was able to nuance the mother's reading of the situation, spelling out that the figure should be taken as a positive sign and testimony to the parents' successful management of their son's diabetes at home.

The blood test complete, it was time to see the doctor. The nurse showed the family into the room where the doctor was waiting, and sat down on a chair. This marked it as a new situation, with the doctor leading the clinical encounter. She began by looking at the boy and asking 'Have you got any questions', but the boy said nothing. Instead, the mother said, 'You do have a question. How long do people have this disease?' The doctor looked at the boy and said, 'You have it all the time, but you're well. You have to take your medicine or you can get very sick.' The nurse filled in by saying 'Did you hear that?' Just as the nurse had initially visualized two bodies, one before and one after treatment began, the doctor's answer to the boy's question also actualized two bodies. If the parents were to successfully treat their son as prescribed, the health service would define him as having a healthy body, meaning almost life as normal before the diabetes diagnosis (Nilsson & Hansson 2016); fail in the treatment and diabetes would emerge again, and the boy would count as ill, which would be reflected in the HbA_{1c} test.

After their opening exchange, the doctor addressed the parents directly to comment on the HbA_{1c} test. Like the nurse earlier, she said 'It's looking good, it's on the right track.' She then explained

HbA_{1c}. Both the doctor and the nurse used the same travel metaphor: the family would travel ahead in time and their hard work would be rewarded with better figures. Metaphors are common in healthcare, used to translate abstract reasoning into more manageable facts (Lakoff & Johnson 1980; Sontag 1989; Gustafsson & Hommerberg 2016). Here too there is another body—a body that is not static but changes over time, and for which parents must invest time and commitment if the HbA_{1c} is to fall within the target values. It is standard for these metaphors to be framed as stories about the future; in the clinical encounter, this is about what the patient, or the family, can achieve if they follow medical advice. Medical advice often takes the form of *instrumental narratives*, focusing on the procedures involved in the treatment (Hansson 2007), as against the stories about the future, which are rather *moral narratives* about the state of health patients and families should aim for, focused on an imagined future in which the patient has improved, and frequently with an ethical dimension about the extent of patient or family responsibility for the disease and its treatment (Ricoeur 1990; Frid 2004). At the same time, in the clinical encounter there is an obligation on patients or families to accept these stories about the reasons for treatment (Hansson 2007).

One such instrumental narrative was the next stage in the consultation, when the doctor moved on from the HbA_{1c} test to the blood sugar data which the family had uploaded with the nurse's help when they arrived at the clinic. When the doctor looked at the figures, shown as a curve on her computer screen, she had nothing but praise for the family's efforts to take responsibility for their son's treatment: 'He's following his curve perfectly; he's following it perfectly,' she said. Since the doctor was so positive, the consultation took another turn as the mother and the doctor went over the Social Insurance Agency paperwork which would allow the mother to be at home with her son a while longer. To bring the consultation to a close, the doctor turned to both parents and said 'Anything else that's happened?' The father now joined the conversation, saying 'There were some weird values where

it shot up,' adding that the nurse had 'told us why, that is that he was going down with something'. The father continued, trying to give a medical explanation for why he thought the numbers odd. The doctor's response to this was not to answer directly, but to ask briefly 'What doses is he on?' The mother gave the insulin doses as a sequence of figures for a twenty-four-hour period. The doctor, looking for an answer, then wanted to know what his afternoon dose was. The mother turned to the father for help but he looked blank, so the mother got out her mobile phone, where she had all the doses noted down. After a little searching she found the value the doctor had asked for. The doctor brought up the day in question on her screen, and looking at it said 'That looks fine to me'. The nurse now joined in, pointing at the value and asking 'Was it that one?' to which the mother said yes, and the doctor once again pointed out 'He's not that low there. You get what we call recoil, because the body counteracts with hormones. Much later you get a higher value,' she added, pointing at the screen.

In this way, moral narratives also surfaced about the family's normal life—their lifeworld (Husserl 2002)—and how it related to the boy's figures. The parents had tried to come up with an answer for what the different figures meant. In the clinical encounter their lifeworld altered so it was now the physician, and partly the nurse, who had the interpretive precedence in explaining the figures. The doctor seemed unworried by the parents' anxiety. In this way, at least two further bodies took their place in the clinical encounter. There was the body the parents dealt with every day, seen when they tried to grasp what they felt was a variety of figures, and there was also a more medicalized body that the doctor could easily define as completely within the hoped-for normal values. The doctor was satisfied with how the parents had taken responsibility for the instrumental narrative—how best to manage the child's diabetes—and in that way had taken responsibility for the moral narrative too.

The mother, though, was not satisfied, and continued to discuss her thoughts about the boy's different figures with the doctor, giving different scenarios from their daily life and explaining her

thinking. The doctor listened and gave her picture of things, while the father stayed out of the conversation. At one point, the mother said ‘We talked it over’ to make it clear she had her husband’s support, but her ‘we’ was largely governed by her being the one at home with their son and shouldering much of the responsibility for his treatment. Thus, there also appeared to be two bodies in the family’s daily life: the mother’s view of the boy’s body as one that had to be cared for; and the father stepping back and entrusting responsibility for the boy’s body to the mother. This view of the boy’s body was also evident in the father’s comment that ‘We’re squabbling a fair bit’ about what figures the boy should have. The doctor tried to help the parents agree, and said straightaway that the boy should be around 6 for a good HbA_{1c}. ‘What I said,’ said the mother, displaying that she was taking responsibility for the child’s body. Towards the end of the consultation, the division became even clearer when it transpired that the mother had been worried by the boy’s body and figures: she said that now ‘I don’t feel that kind of stress’ about the figures, and the doctor praised her with the words ‘That’s good, important,’ while the father added, ‘You’ve calmed down.’ The mother’s response was ‘Thank you,’ to which the doctor said, ‘It’s a lot,’ referring to the burden carried by the mother on a daily basis.

With Mol’s concept (2002) of the body multiple, we can see how one and the same body can be interpreted and understood in different situations, and that it affects—enacts—how each individual relates to the figures from that body. The figures are thus not only a form of standardized knowledge, circulating freely in the clinical encounter, but to a far greater extent they also have the character of things, shaping and shaped by the individuals who use that knowledge (Agamben 2014). These are the same figures that the doctor, nurse, mother, and father see, but they all seem to respond differently. Here, the worries voiced by the mother are perhaps most revealing about her adoption of a mothering role, where the figures—the *dispositif*—seem to speak to her concerns about their child’s health and well-being (Agamben 2014). Blood sugar levels

are now central to her lifeworld, but HbA1c was in a way proof of whether she had succeeded or not. HbA1c is not only a value that categorizes the child's body, it also recruits the mother into caring for that body. Measurements and standardization thus create not only standardized knowledge of the child's body in a variety of situations, but also the subjectification processes by which the mother evolves a specific form of self-care for the child's body, with HbA1c the ratification process that distinguishes this body from the rest as an autonomous object in the world, and simultaneously creates a desubjectification process whereby the mother is drawn into that specific form of self-care (Agamben 2014). The self-care the mother has to adhere to is of the medical professionals' making, and in the clinical encounter she does not get across her realities in her own lifeworld, whether to her husband or to the doctor.

The figure of 52 is expressed in various ways in the clinical encounter, being bound up with the medical narratives and practices that the parents relate to in their lifeworld (Kleinman 1988). A central perspective when critiquing how medical 'facts' become autonomous things, being dispositif in our daily lives, is Edmund Husserl's *Die Krisis der europäischen Wissenschaften und die transzendente Phänomenologie* of 1936. He described 'psychologism' as a discipline that distorts the human subject within its own lifeworld; his was a critique of modernity and of how it generates the desubjectification processes that alienate, here, the patient and their relatives in their own lifeworlds.⁸ There is no need to claim that the figure of 52 distorts the family in their lifeworld for us to use the perspective to identify the practices changed and renegotiated in the clinical encounter, where the medical perspective prevails at the expense of the family's personal experience. It should be recognized that standardized knowledge not only is generated in the clinical encounter, but has obvious power differentials there, and impacts how the family sees the doctor and the nurse.⁹ Despite the criticism, as this particular consultation drew to a close the parents seemed satisfied. They had been given new information to take home, where they would continue caring for their son in the best manner possible.

The professionals and 52

To understand why the figure of 52 is so important in the clinical encounter, we must look beyond patients and families' needs for information in managing diabetes in their daily lives. The figure is also of great importance for how medical staff, and especially doctors and nurses, think and talk about what they do. As we have seen, HbA_{1c} today is comparable not only individually, but also as a metric of all the diabetes clinics in the country, and thus a control mechanism—'know-how'—for relations between various clinics, between clinics and hospital management, between clinics and government, between clinics and patient associations, and so on (Rose & Miller 1992). As the literature has found, it presents the opportunity to manage a clinic from a distance, for example by defining the range of target values the clinic should meet (Latour 1987; Bloomfield 1991). Here 52 is little more than a control mechanism that determines hospital care by labelling specific forms of performance in the health service (Tøndel 2017).¹⁰ A key point in this is found in the literary analyses by Knut Ove Eliassen (2008), who writes that naming—in the sense of designation—is not only about giving people individual identities that make it possible to follow them throughout their lives, but is also about identifying things. It is by naming that the world becomes understandable to an organization, while the organization is distanced from the world by the act of naming. Eliassen's point is similar to the subjectification and desubjectification processes already described, but here the focus is instead the organization (Nilsson & Sjöstedt Landén 2017).

The question of HbA_{1c} arose at the first staff meeting I observed. Although the meeting was about something else, they still ended up discussing the figure of 52 and whether the clinic should work to have the best average value in Sweden, which was not then the case. The doctor who was head of the clinic said that 'We're going to be the best team in Sweden', and that they should work to allow patients to become independent, supported with the correct knowledge to manage their diabetes. The fact that the lead doctor could even

suggest it was because the clinic had joined a network of diabetes clinics across Sweden, where each submitted their HbA_{1c} averages and thus made themselves comparable—a control mechanism for the clinics, as the figures determine a number of their priorities. Also, however, this had given rise to certain idioms. Some of the medical staff had attended a national conference where various clinics' averages had been compared, and at a staff meeting on their return said 'It's fun that the HbA_{1c} has gone down', while another interjected 'It's nice, it takes a while to see the change'.

To achieve this goal, the endocrinology department would have to be unequivocal with families and patients about the blood sugar levels they were to aim for. At the staff meeting, one nurse responsible for the HbA_{1c} work said that the clinic 'should continue working on high HbA_{1c}', supporting families who have not got their child's diabetes treatment under control. One way was to be clear with families and give them the leaflet discussed at the start of this chapter, as it spells out the guidelines the clinic expects families to follow in daily life. One of the doctors said how important it was to 'show the document to those who are going over 60', indicating it was crucial to identify the patients who needed extra help. The figure of 52 was thus not only a control mechanism that shaped the clinic's operations, but also served as a marker for those patients who failed to meet the target.

It was imperative that staff identify and engage with families and patients who fell outside the target values, as their health was at risk of deterioration and they needed extra support in their self-care, and they pushed up the clinic's average HbA_{1c}. One late afternoon, shortly after one of the staff meetings I observed, I was walking with some of the doctors and nurses through the hospital. They were chatting a little more freely as it was not a formal meeting, and the conversation turned to the clinic's 'duffers', who had poor HbA_{1c} values and glucometer readings that were all over the place, and who doctors felt were not telling staff the truth about how they managed their diabetes. In informal conversation, these patients became actors who not only risked their own health, but

also ensured the clinic had worse results than the other clinics in Sweden. One of the staff said that it only took a single patient like that to affect the clinic's national ranking.¹¹

The healthcare professionals kept coming back to this form of categorization, worrying about how to get medical information across to patients and families. There was one such dialogue at a staff meeting about coming to grips with patients who failed to meet the guidelines set by the endocrinology department. One of the doctors noted that one particular family was finding things exceedingly difficult, because the father had diabetes too and never checked his blood sugar and the mother had cancer. Their son's blood sugar levels were worrying, and the doctor asked 'Who is going to support this boy?' The doctor's suggestion was to try a home visit. Another of the doctors, picking up on the idea, said 'I think you're absolutely right, we have to find new ways. But at the same time, hospital appointments are important for getting things to work.' The first doctor's response was that 'For some it feels utterly pointless. This is a patient who needs help making treatment part of normal life.' One of the nurses said home visits that should not be routine, but could be an important 'tool in the toolbox'. A third doctor suggested 'finding an ally at the school', but the nurses pointed out that it needed considerable effort to make that work. The doctor who sparked the discussion ended it by saying 'Those with a high HbA_{1c} are the ones we haven't reached; if we had, we wouldn't have them.'

In the discussions between the medical staff the notion of an ideal family can be glimpsed—one that has developed its self-care, and with it not only an understanding of the diabetic child's body, but also of how the family can take responsibility for the diabetes treatment. Yet there are also those who fall outside this, where neither the family nor the child seems able to take responsibility as the medical staff wish they would: they lack what in healthcare is known as compliance (Arduser 2017). It is as if these bodies defy the clinic's ways of categorizing and organizing patients, and are instead identified as anomalies that must be persuaded back into

the system one way or another. Many of the meetings I observed were about how doctors, nurses, dieticians, or counsellors could best talk to these patients and families: how to teach them and how to reach out to them in their lifeworlds. Central to this was individualized care, tailored to meet the needs of the individual or family ‘where they are’, and at the same time give them the tools to make their own decisions—but it was obvious that not all families were anywhere near that. As for the more problematic patients—the ‘duffers’—staff could report them to social services as a final recourse. As one of the doctors said at a staff meeting, she ‘doesn’t report the ones who are finding it hard going as long as they’re not stropy’, but at the same time she wondered aloud, ‘How long can they be up at 110?’ None of those present ventured to answer, but all understood the trouble with such a high figure when the goal was for everyone to be 52 or below.

What my ethnographic cultural analysis shows is there is a form of enactment, as Mol (2002) points out, which is influenced by the tools the staff can enact with. There are no predetermined subjects, for they are created by the healthcare practices, whether a staff meeting or a clinical encounter. Here Mol, invoking Judith Butler in *Gender Trouble* (1990), notes that the subject ‘is not given but practiced. The pervasive and mundane acts in which this is done make people what they are’ (2002, 37). HbA_{1c} is just such a tool in the medical practices where the body multiple is defined and categorized as a form of enactment, and thus appears as normal and unproblematic—or as an anomaly that the healthcare system must work particularly hard to bring back into the medical fold. Central to Mol’s theory (2002) is her argument that medicine is nothing if not an exercise in power, where the strongest form of enactment is the one that can be imposed. In this she is informed by Bruno Latour’s dictum that ‘The strongest reason always yields to the reason of the strongest’ (Latour 1993, cited in Mol 2002, 108). The strongest reason identified here would appear to be the figures—the dispositifs (Agamben 2014)—for HbA_{1c}, and their power to categorize bodies according to practice, and thus to enter

the lifeworlds of patients and families, affecting their relationship with the treatment and a normal life with diabetes. This form of categorization seems based on the healthcare system's requirements, though, and not necessarily the patients' or the families' best interests, despite the patient's best interest being the first thing any healthcare professional would point to as the reason it is so important to track HbA_{1c} and blood sugar levels. The standardized knowledge associated with the figure of 52 directly affects how bodies—in this chapter seen as bodies multiple—are categorized and related to in different practices.

Conclusions

The figure of 52 is found in this chapter to be a thing, a *dispositif*, which exerts a centripetal force on a range of practices in Swedish diabetes care and beyond. It is not only a figure for patients and families to aim for in managing the disease, it also generates a relationship of sorts between them and medical staff, *and* it affects healthcare provision and how staff design patient care and categorize patients. The result is that 52 is an ethnographic route to understanding how today's medicine objectifies, measures, and standardizes the diabetes care on offer. In the chapter, this is discussed in terms of subjectification and desubjectification processes, where patients, families, and staff are all subject to the HbA_{1c} test's ordering of reality (Agamben 2014). While the figure engenders practices which the actors should enact in their everyday lives—at home or in hospital—it simultaneously renders other practices impossible.

Central here is the fact that the figure of 52 can be considered standardized knowledge. This form of knowledge is not necessarily mutable or even mouldable; rather, it is locked into a specific state of knowing about what diabetes is and how it should be best treated. Standardization makes it awkward for patients, families, and staff to question the figure, and so it continues as a point of reference, as something to comment on or relate to. HbA_{1c} not only generates and controls a number of practices, but those practices

are self-sustaining and can be said to underscore the significance of the figure of 52 in diabetes care. Given the way HbA_{1c} has been used, its standardizing function is fixed, confirming it as the key perspective in healthcare of this type.

Diabetes care is just one of many examples of healthcare where we can see a similar trend, with figures being increasingly central to standardized knowledge processes of all kinds. To some extent, this development has been driven by new control mechanisms in healthcare and digitalization. Today's healthcare control mechanisms are designed to turn healthcare practices not only into categorizable figures, but also into figures that can be followed up and compared; and different strategies can be chosen according to how the figures are categorized (Pollitt & Bouckaert 2000). It is in its figures the organization manifests itself and thus exercises a degree of control over its operations (Bornemark 2018). But it is not only in relation to its organization that figures have become increasingly central to the health service; in the form of quality registry data, figures are essential in shaping views of specific diagnoses or whether a treatment should be retained or altered (Lindh & Rivano Eckerdal 2016). Ongoing digitalization has made it easier to compile large quantities of data and compare them by patient, by clinic, or by region. Without digitalization, it is hard to imagine that this particular standardized knowledge could have expanded as it did. Many patients' HbA_{1c} readings, combined with other facts and figures over prolonged periods makes it possible to compare, develop, and change healthcare.

The significance of 52 thus stems from the practices in which it operates, and with the help of Mol's perspective (2002) we can discuss the body multiple and its interpretations, which vary from practice to practice. The concept of the body multiple is an indication of how standardized knowledge is coded and embedded in a context with multiple exclusion mechanisms (Foucault 1993), where some perspectives are defined as problematic or are rendered invisible, while others are categorized as important. This *dispositif* offers actors the prospect of action while eliminating other activities,

so that actors are subjected to the way HbA_{1c}—or the figure of 52—arranges reality.

The purpose of this chapter has been to examine how figures can create normative guidelines in a medical setting, and how they are interpreted and used according to their contextual practices, setting out in brief what these normative guidelines might mean. However, as is evident from the ethnography, there is also the crucial factor that standardized knowledge does not in any way, shape, or form standardize the lived lifeworlds of patients, families, and staff. Rather, the figure of 52 is something to relate to, for it is only then the figure is set in motion, knowledge and all.

Notes

- 1 In Sweden, where the study was conducted, the public health service is the responsibility of 21 health regions. There are thus variations in organization and supply, but in most regions all non-hospital care is free for children and adolescents under the age of 20. Prescription medicines are free for those under the age 18, as are most medical aids.
- 2 The target value was subsequently reduced and at time of writing is 48 mmol/mol.
- 3 The HbA_{1c} test requires expensive equipment—not something a family can have at home, although they can take blood samples at home and send them in to a pathology laboratory. In most Swedish hospitals the HbA_{1c} test machine is in the diabetes clinic, where it is convenient for patients to be tested during regular appointments.
- 4 The leaflet is above all a document (Buckland 1997, see Markus Idvall's chapter in this book)—and an element in the *dispositif*—which can create a variety of values for families. To be handed the document can be the closing ritual of a clinical encounter (Whyte et al. 2002); it might be thought a gift of trust which the family now has to take responsibility for (Mauss 2001); it can be a non-human actor linking the family's actions with the health service (Latour 1992). In my thesis (Hansson 2007), I write about another class of medical document with similar characteristics: prescriptions. A prescription too can act as a closing ritual, leaving the patient at the end of a consultation feeling positive about their medical problems (Whyte et al. 2002, 123 ff.), and in the position to actualize their treatment with their own personal medical object. But like any medical object, a prescription also refers to the doctor and their instructions, 'freezing' the spoken word as writing or thing, which only enhances the doctor's authority.
- 5 Gabriella Nilsson and I have drawn attention to this elsewhere, arguing that its effect is to encourage families to alter their view of their child's diabetes from a disease perspective to a lifestyle perspective, where the disease, rather than a limit on life, is seen as part of life (Nilsson & Hansson 2016, 262).
- 6 A lifeworld is also commonly equated with morphological structure, for even though

- it is an inaccurate, intersubjective consciousness, the lifeworld still builds on scientific knowledge or countenances scientific knowledge (Wallenstein 2011).
- 7 This is a form of desubjectification: it is virtually impossible for the family and the patient to avoid the dispositif, and instead they are subject to HbA1c's specific way of ordering reality (Agamben 2014). As per Martin Heidegger (2013), this process is a form of alienation that modern people can extricate themselves from only with difficulty.
 - 8 Alienation is the term Karl Marx (2018) coined for his critical theory of modernity, and it can also be found in Husserl (1993), albeit with a slightly different meaning. In this chapter, it is applied to the dispositif, and with it the web of power which envelopes the individual, but which may be difficult to see or criticize (Agamben 2014; see also Heidegger 2013). These systems of power can be capitalist—Marx—or scientific—Husserl.
 - 9 In this I follow Michel Foucault's argument (2003) that power creates counter-power, but it is for another occasion to explore what patients and families can do in the face of these power structures.
 - 10 This is comparable to the umbrella term of new public management, which describes how public services mimic business organizations, for example by defining metrics as targets to be followed up and evaluated (Pollitt & Bouckaert 2000; Karlsson 2017).
 - 11 Not that staff could not provide excellent care for their patients otherwise—during my fieldwork, for example, I heard of a doctor who had his mobile phone on out-side working hours so patients and families could ring for help in managing daily life—but rather it marks a form of (de)subjectification process, by which healthcare professionals subjectify individuals and take extra care of them, while desubjectifying them by translating them into figures and values to be managed.

References

- Agamben, Giorgio (2014), *Vad är ett dispositiv?* (Malmö: Eskaton).
- Alftberg, Åsa & Kristofer Hansson (2012), 'Introduction: Self-care translated into practice', *Culture Unbound: Journal of Current Cultural Research*, 4, 415–24.
- Arduser, Lora (2017), *Living chronic: Agency and expertise in the rhetoric of diabetes* (Columbus: Ohio State University Press).
- Beckman, Anita (2009), *Väntan: Etnografiskt kollage kring ett mellanrum* (Gothenburg: Mara).
- Bloomfield, Brian P. (1991), 'The role of information systems in the UK national health service: Action at a distance and the fetish of calculation', *Social Studies of Science*, 21(4), 701–734.
- Bornemark, Jonna (2018), *Det omätbaras renässans: En uppgörelse med pedanternas världsherravälde* (Stockholm: Volante).
- Buckland, Michael K. (1997), 'What is a "document"?', *Journal of the American Society for Information Science*, 48(9), 804–809.
- Butler, Judith (1990), *Gender trouble: Feminism and the subversion of identity* (New York: Routledge).
- Ehn, Billy & Orvar Löfgren (2010), *The secret world of doing nothing* (Berkeley & Los Angeles: University of California Press).

- Eliassen, Knut Ove (2008), 'Tingens tale: Epistemologi, estetikk og eksistens hos Michel Foucault', *Norsk filosofisk tidsskrift*, 43(4), 290–303.
- Fioretos, Ingrid, Kristofer Hansson & Gabriella Nilsson (2013), *Vårdmöten: Kulturanalytiska perspektiv på möten inom vården* (Lund: Studentlitteratur).
- Foucault, Michel (1978), *Histoire de la sexualité*, i: *La volonté de savoir* (Paris: Gallimard).
- (1993), *Diskursens ordning: Installationsföreläsning vid Collège de France den 2 december 1970* (Stockholm: Brutus Östlings Bokförlag Symposion).
- (2003), *Övervakning och straff: Fängelsets födelse* (4th rev. edn, Lund: Arkiv).
- Frid, Ingvar (2004), 'Att ta del av en berättelse: En resa mot okänt mål', in Carola Skott (ed.), *Berättelsens praktik och teori: Narrativ forskning i ett hermeneutiskt perspektiv* (Lund: Studentlitteratur).
- Frykman, Jonas & Nils Gilje (2003), 'Being there: An introduction', in eid. (eds.), *Being there: New perspectives on phenomenology and the analysis of culture* (Lund: Nordic Academic Press).
- Gadamer, Hans-Georg (1996). *The enigma of health: The art of healing in a scientific age*. Cambridge: Polity Press.
- Gustafsson, Anna W. & Charlotte Hommerberg (2016), "'Pojken lyfter sitt svärd: Ger sig in i en strid han inte kan vinna': Om metaforer och kronisk cancersjukdom", *Socialmedicinsk tidsskrift*, 93(3), 271–279.
- Hacking, Ian (1999), *The social construction of what?* (Cambridge, MA: Harvard University Press).
- Hansson, Kristofer (2007), *I ett andetag: En kulturanalys av astma som begränsning och möjlighet* (Stockholm: Critical Ethnography Press).
- (2013), 'En mångfaldig forskningsetik', *Rig*, 164–70.
- Heidegger, Martin (2013[1927]), *Vara och tid* (Gothenburg: Daidalos).
- Husserl, Edmund (1993 [1936]), *Husserliana: Gesammelte Werke*, xxix: *Die Krisis der Europäischen Wissenschaften und die transzendente Phänomenologie, Ergänzungsband, Texte aus dem Nachlass 1934–1937* (Dordrecht: Kluwer).
- (2002 [1913]), *Husserliana: Gesammelte Werke*, xx/1: *Logische Untersuchungen: Ergänzungsband: Entwürfe zur Umarbeitung der VI. Untersuchung und zur Vorrede für die Neuauflage der Logischen Untersuchungen* (Dordrecht: Kluwer).
- Karlsson, Tom S. (2017), *New public management: Ett nyliberalt 90-talsfenomen?* (Lund: Studentlitteratur).
- Kleinman, Arthur (1988), *The illness narratives: Suffering, healing, and the human condition* (New York: Basic).
- Lakoff, George & Mark Johnson (1980), *Metaphors we live by* (Chicago: University of Chicago Press).
- Larsen, Tord & Emil A. Røyrvik (2017), introduction to eid. (eds.), *Trangen til å telle: Objektivering, måling og standardisering som samfunnspraksis* (Oslo: Scandinavian Academic Press).
- Latour, Bruno (1987), *Science in action: How to follow scientists and engineers through society* (Cambridge, MA: Harvard University Press).
- (1992/1998), 'Teknik är samhället som gjorts hållbart', in id., *Artefaktens återkomst: Ett möte mellan organisations teori och tingens sociologi* (Stockholm: Nerenius & Santérus).
- Alan Sheridan & John Law (1993 [1988]), *The pasteurization of France* (Cambridge, MA: Harvard University Press).
- Lindh, Karolina & Johanna Rivano Eckerdal (2016), 'Livsdugliga data i gränslandet mellan vård, styrdokument och teknik', *Socialmedicinsk tidsskrift*, 93(3), 297–305.

- Marcus, George E. (1995), 'Ethnography in/of the world system: The emergence of multi-sited ethnography', *Annual Reviews of Anthropology*, 24.
- Marx, Karl (2018 [1867]), *Kapitalet*, i: *Kapitalets produktionsprocess* (7th edn, Lund: Arkiv förlag/A-Z förlag).
- Mauss, Marcel (2001 [1902]), *A general theory of magic* (London: Routledge Classics).
- Mol, Annemarie (2002), *The body multiple: Ontology in medical practice* (Durham: Duke University Press).
- Nilsson, Gabriella & Angelika Sjöstedt Landén (2017), 'Arbetslivsetnologi: Professioner i nyliberala organisationer', *Kulturella perspektiv: Svensk etnologisk tidskrift*, 26, 2–7.
- Nilsson, Gabriella & Kristofer Hansson (2016), 'Berättade fantasier om förr, nu och framtiden i vården av barn med diabetes', *Socialmedicinsk tidskrift*, 93(3), 261–270.
- Pollitt, Christopher & Geert Bouckaert (2000) *Public management reform* (Oxford: OUP).
- Prout, Alan (1996), 'Actor–network theory, technology and medical sociology: An illustrative analysis of the metered dose inhaler', *Sociology of Health & Illness*, 18(2), 198–219.
- Ricoeur, Paul (1990/1994), *Oneself as another* (Chicago: University of Chicago Press).
- Rose, Nicolas & Peter Miller (1992), 'Political power beyond the state: Problematics of government', *British Journal of Sociology*, 43(2), 173–205.
- Skott, Carola (2013) (ed.), *Människan i vården: Etnografi, vård och drama* (Stockholm: Carlsson).
- Sontag, Susan (1989), *Illness as metaphor and AIDS and its metaphors* (New York: Picador/Farrar, Straus & Giroux).
- Tøndel, Gunhild (2017), 'Omsorgens håndtrykk i scener rundt tall', in Tord Larsen & Emil A. Røyrvik (eds.), *Trangen til å telle: Objektivisering, måling og standardisering som samfunnspraksis* (Oslo: Scandinavian Academic Press).
- Wallenstein, Sven-Olov (2011), 'Husserl, tekniken och livsvärlden', *Fenomenologi, teknik & medialitet*, 21–54.
- Whyte, Susan Reynolds, Sjaak van der Geest & Anita Hardon (2002), *Social lives of medicines*. (Cambridge: Cambridge University Press).