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Author	C.W.M. Dedding
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Summary

Sharing in power and powerlessness describes the daily life of children from 8 to 14 years old who have diabetes, and how these children can and want to participate in the treatment of their disease. The first starting point was that children are not passive recipients of care, but actors that can and do give their own meaning and direction to life with diabetes. The second starting point is the fact that a disease – essentially something that disrupts your everyday life – is not something that you have, but something that has to be managed. International and national laws state that children have the right to participate in the decision-making processes that concern them, and government policies increasingly aim towards allowing patients to play a greater role in healthcare. Nonetheless, some medical professionals feel that as children do not yet possess the necessary competencies to participate, or have no interest in the process and prefer to play, it would be inefficient to include children in the already limited time available for consultations, or consider that parents would prefer to speak on their behalf. As these examples illustrate, the lives of children with diabetes, and the degree of their own participation, are intricately connected with the ideas and practices of medical professionals. Therefore, in this thesis I have not only described the everyday life of these children with diabetes, but also how the power and dependency relations between children, parents, and medical professionals shape the lives of these children. I show how these relations commence, and what the consequences can be for the degree to which the cooperation between children and adults is carried out successfully, something which for diabetes is so exceptionally necessary.

The everyday lives of children, and the power and dependency relations between children, parents, and medical professionals, have been examined in this research using a two-sided approach: on the one hand via a classic ethnographical study, and on the other by inviting children as co-researchers in a parallel participatory action research. A participatory research route, I thought, would not only explicitly place the child's perspective at the fore, but also offer opportunities to learn about the cooperation between adults and children. Moreover, a participatory route provided the opportunity to work together with these children in an intense and extensive way, thus creating opportunities to observe how diabetes interferes with their day-to-day life, and how they anticipate this and react to it.

Chapter 1 describes the backgrounds, goals, and theoretical framework of this study. Special to the treatment of diabetes is that it is just partially carried out by medics and rarely takes place in a hospital; the largest part of the treatment is carried out by patients in their

own environment. On a daily basis, people with diabetes are expected to find a balance between nutrition, exercise, and insulin. They have to take insulin via injections or an insulin pump, because the body creates too little or, in the case of most children, no insulin. Considering the fact that most patients have a large influence over their own treatment, its success is not solely dependent on the qualities of the medical professionals, but also on the care qualities of children and parents, and how these different parties cooperate. But little is known about this cooperation, or the perspectives of children and their everyday life with the illness. In other studies, children have been involved via questionnaires aimed at understanding their quality of life or 'coping', for instance, but seldom have they had the opportunity to share their experiences, visions, and worries from their own perspective.

In order to analyze the power and dependency relations between children and adults in diabetes healthcare, a Foucauldian perspective on power has been utilized. In this approach, power is not a possession or tied to positions, but is a relational phenomenon that can be described as a localized, strategic, invisible and diffuse relation (Lupton 1994, Petersen & Bunton (eds.) 1998). Moreover, power is not only perceived as stringent and normative, but also as voluntary and productive (Foucault 1984b). Even though the Foucauldian perspective is functional for gaining an insight into the workings of power mechanisms, both in a restrictive and a productive sense, it has its shortcomings when used to analyze how children, parents, and medical professionals experience these practices, and how they play an active part in them. This is especially so given that actor-ship within hegemonic discourses and practices is central in this thesis. Therefore, in addition to the Foucauldian perspective, I make use of the 'agency' concept. This concept can be defined in common terms as the strategies that actors use both in relation to dominance and unequal power relations, and to realize their personal goals (Ortner 2006).

In the analysis of power and dependency relations, I give attention to the cooperation between people, but also to the role of medical technology. Inspired by the work of, among others, Akrich (1992), LaTour (1993), Van der Geest & Hardon (1994) and Yearly (2005), the assumption is that 'who, when, and how someone is able to dispose of, produce, and use technology' influences the participation possibilities in healthcare.

Chapter 2 describes the ideology behind the participation discourse. The term 'participation' seems to have acquired mythical proportions; nowadays it is a very fashionable word to use when discussing issues like healthcare, education, development cooperation, the environment, youth policies, and employment. However, participation is

not simply a new way of working, a method that just has to be installed. It is a value, a way of looking at how people relate to each other, and who has a say in what (Hart et al. 2004); a value also shaped in dialogue with the different stakeholders and in different contexts and situations that they find themselves. But little is known, especially regarding this interactive process, about how participation within organizations or within a community is shaped, nor about the effects of participatory processes on the different participants and organizations, and how you can assess these effects. Moreover, the power aspects that characterize each participatory process have not yet been critically examined (Chung & Lounsbury 2006, Cooke & Kothari 2004). This raises the question of whether there really is something like a shifting of power, or whether it is a myth gladly supported by researchers and policymakers.

Chapter 3 offers an insight into how I, together with children with diabetes, made the transition from the ideology of participation into practice. Children with diabetes type 1, between the ages 8 to 12, coming from three Amsterdam hospitals, were invited to jointly define a core problem, develop an intervention, and evaluate this with fellow sufferers of diabetes from two hospitals outside the region of Amsterdam. Besides my role as a facilitator and evaluator of this intervention route, I developed some of my own research activities to gain an insight into the experiences and lifeworlds of children, and the power and dependency relations between children, parents, medical professionals, and other adults. These activities consisted of, among others, a literature study, six months of participatory observation in the polyclinic treatment setting, and semi-structured interviews with children, parents, and medical professionals.

In this method chapter, I also reflect upon my position as a researcher, the ethical aspects of the research, and the feasibility of the study and the chosen methodology, including the methods I specifically developed for this research. I conclude that target group participation is largely dependant on the attitude of the researcher, and to a lesser extent the chosen research technique (cf. Cornwall & Jewkes 1995). During the process, two tension fields arose. The first tension field concerned prioritizing the children's perspectives, for it led to a disruption of that which was considered normal: the relation between children and adults. A second tension field occurred between the value that was attributed to lay knowledge compared to professional and scientific knowledge and norms. In chapters 7 and 8 I discuss these tension fields further.

How children experience, interpret, and manage their condition and its treatment is the central theme in chapters 4, 5, and 6. In chapter 4, I show how children, parents, and

medical professionals work together at one therapeutic plot. This jointly produced plot explains the connection between clinic activities, but also how these activities are communicated, what can be expected of the treatment, and what everyone's role and responsibility is in this. This plot can be summarized as 'you can lead a normal life with diabetes' or, in the children's terms, 'I can do everything'. I show that this positive plot forms a functional co-production that is meaningful for all parties: children, parents and medical professionals. Nonetheless, this positive plot has its downsides. Firstly, a lot of effort has to be put into maintaining this plot, and secondly, this plot overshadows a counter-plot that can be defined as 'diabetes is like a prison'. In other words, it marginalizes the negative aspects of diabetes, and the problems that children encounter in everyday life.

In chapter 5 I describe in detail the kind of work children with diabetes have to do. The opinion of medical professionals and producers of diabetes technology – that the diabetes regime can easily be fitted into one's daily life and that it only brings along some minor discomforts – does not do justice to the visible and invisible sick work that children and parents have to do on a day-to-day basis. The visible sick work consists of measuring blood sugar and injecting insulin several times a day; a demanding task because these are procedures that have a major impact on the boundaries and the integrity of the body. Invisible sick work concerns the anticipation of tasks that need to happen, such as injecting on time, measuring, eating right, but also of the things that could go wrong like a 'bad' measurement, an unexpected hypo or hyper, and all the emotional, social, and practical consequences that are the result. Invisible sick work is also about balancing the different interests, with the requirements of the treatment regime on the one hand, and the desire to lead a normal life on the other. Both the invisible and the visible work cause interruptions in the well-being of children and parents, in the flow and implementation of activities, and in social relations. The sick work that children do is underestimated, in my opinion, due to the fact that this work literally takes place outside the view of the medical professionals. In addition, the image of children as vulnerable and passive recipients of care, who should have a trouble-free childhood in which worrying and working is something that should be done by adults, does not fit into the positive therapeutic plot, which itself is contributed to by the way in which new technology is promoted.

Chapter 6 describes the participation desires and possibilities of actors in the polyclinic consultation. The chapter begins with Mark, a boy who, visibly bored, sits in front of a nurse's desk. It is a recognizable image for many parents and medical professionals, and raises the question: do children want to participate, or would they rather be left alone to

play? Analyses show that children, parents, and medical professionals are positive towards child participation, but that this should not be taken too literally. For instance, children do not always want to participate in each and every discussion. Further, it often seems that parents and medical professionals, in practice, tend to put their own vision and worries first and make them weigh heavily in the decision-making process. Thus the uncertainty and doubt that children express if and when they are allowed to participate or co-decide in practice is not unwarranted; and the same is true for medical professionals' and parents' questions of whether children even want to co-decide. This ambiguity is expressed through the behaviour of silent and bored children, who feel that they are not allowed to participate or that their attempts to do so are senseless, and through verbally active parents and medical professionals who feel that children are not interested at all. Thus, a self-reinforcing process is created.

Because verbal participation does not seem successful, or because they lack the courage to do so, children find creative ways to do justice to their feelings and experiences. One of these ways is by nodding in approval in the consultation room, but acting entirely on their own experience and insights outside the hospital. The effectiveness of this common strategy is limited, for it means that children and parents cannot sufficiently use the knowledge and experience of the medical professional, and that this professional cannot tune the treatment and education to the life of the child (cf. DiMatteo 2004). Moreover, due to this behaviour, experiential knowledge is either not available, or not available enough, for the purpose of questioning the treatment, nor can it be of help for other patients. This learning process for medical professionals cannot be realized before the daily life of children becomes more of an issue, and children interacted with as knowledgeable actors; only by doing so will children be willing to share their personal experiences, which are so very crucial for the success of treatment.

In chapters 7 and 8 I further analyze the two themes put forward in the previous chapters: 1) the need for control, and 2) the social-cultural construction of what a child is and can do. In chapter 7, I show that the search for control, and who has to control what, is looked at differently by children, parents, and medical professionals. For all parties it goes that knowledge gained through experience, often over the years, has little value in the control network. Yet it is the knowledge-through-experience of the medical professionals and children that could allow for the questioning of the dominant control discourse: the degree to which control is feasible with current knowledge and treatment, but also how controlling blood sugar levels relates to other goals in life, the complex body, and day-to-day life. In

listening to the stories of medical professionals, children, and parents, it is not hard to discover that the dominant control discourse not only creates power, but also feelings of powerlessness, frustration, failure, and guilt, for it is a discourse that is inherently difficult to put into practice. Yet at the same time, the control discourse is productive: it partially makes sure that children with diabetes can lead a relatively healthy and good life, because it helps them to live up to the demanding treatment regime which is so very important for their condition. Moreover, an analysis of the power sources which children have at their disposal indicates that social processes in the medical arena and outside it are not so closely determined by impregnable institutional structures or medical professionals. The dominant image of a child as passive and fragile presupposes and supports the belief that there is and should be control over the child, but paradoxically it also provides agency to children and absolves them from blame.

In chapter 8, I look more closely at the social-cultural construction of what a child is and what they can do. The reason this chapter came about was due to the recurrent remarks made by adults about what children *cannot* do. By using the concept of 'othering' I research where these generalizations about the capacities of children (and child patients in particular) come from. The essence of the argument is that the difference between children and adults has been made unnecessarily large. This process that I call 'othering' has its consequences for how adults (are able to) assess the competences of children, but also how children are approached as an individual, patient, informant, or as a colleague-researcher. It also has consequences for the quality of healthcare they receive and how children experience this care, because: 1) it leads to an interaction that puts the adult's desire for control and protection first; 2) it makes it hard to personalize the child, and to assess it according to its own individual competences; 3) it makes it especially clear that children are different, but not how children and adults are similar; and 4) it contributes to the fact that children are not recognized as actors. It undervalues the knowledge and capacities of children, their emotional and practical needs, but also how close children are to 'us' (adults).

In chapter 9, I return to the participatory research process to analyze what happens when we use the knowledge, skills, and problem experiences of children as our primary starting and focal point during the entire research process. Firstly, I ask myself the critical question of whether I/we really succeeded in taking the knowledge, skills, and needs of children as our primary focal point during the research. I conclude that the necessary power shift was hard to realize in practice, but that nonetheless the desired participation level was achieved, and even more significantly, has been meaningful to the target group. I describe how the

process and the products that we developed – a book, a rap, a short documentary, and a teaching kit – have contributed to the empowerment of children and how the developed products differ from products already on the market for children with diabetes. The products will be elaborated upon in additions 3, 4, and 5.

In chapter 10, the conclusion, I return to the assumption that children with diabetes want to and can participate, and that their participation will be beneficial for both the quality of the healthcare and the quality of the research. These are assumptions that can be looked at from a different perspective by examining the work of Van Trappenburg (2008) and Mol (2006). They have shown that the participation discourse has led to some undesired, even though unintended, side-effects. A side-effect that this research has unveiled was that, on the one hand, the term participation itself suggests that there are practices which certain groups cannot, or cannot sufficiently, be part of, (though they should be able to); or from a more radical view on the other hand, that some groups should be empowered to confront and overthrow certain practices. Both the mild and the radical ways of thinking about participation suppose that there is a gap between two parties, making them opposites to each other – a low power group versus a practice with one or more dominant parties – and this dichotomy is constructed in the participation process itself. Both ways of thinking deny the fact that these low power groups, in this case children, are already part of the practice, and suggest that some groups have power and some do not. I have shown that children play an active part in practices related to their diabetes healthcare, including in those practices where their perspectives, knowledge, experience, and desires are not actively welcomed, recognized, or examined. I have also shown that the fact of not actively inviting children into the decision making processes that concern them cannot be attributed solely to the unwillingness of medical professionals and parents, but to a whole complex of factors, among which are the therapeutic plot, the invisibility of sick work that children do themselves, the way in which the polyclinic consultation goes and is directed, and the socially dominant image of children.

By approaching child participation as already part of existing practices and processes, something I describe as an 'integral vision to participation', not only do the differences between children with diabetes and their medical professionals become clear, but also the similarities. Both possess sources of power, but both are also powerless and vulnerable in relation to diabetes care, and in relation to each other. Firstly, the powerlessness is confined to the (for now) impossible task of wanting and being able to intensively subject an individual body to a lifelong process of control. A second source of powerlessness lies in

the social-cultural construction of what a child is, and what it can do. This construction makes it hard to value the individual competencies of a child with diabetes, and to recognize their needs, problems, and agency. Finally, a third source of powerlessness is the limited status of the perspectives and the knowledge-by-experience of patients within the healthcare system, which causes treatment goals and scientific research to be defined and evaluated in an overly one-sided way. The experiential knowledge and logic of children and patients should not only be systematically examined more often, but should also assume a place in the practice of medicine as well as in guidelines, textbooks, and training.