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Revealing the hidden agency of children in a clinical setting

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Abstract

Background Interactions with children in clinical settings are often criticized because parents and medical professionals speak for children rather than to them. Such approaches do not take the agency of children into account.

Objective First, to examine how children enact agency in a clinical encounter and draw lessons from this to improve health-care practices for children and, second, to explain how looking at agency might help to move the participation agenda forwards.

Design A qualitative study incorporating a range of methods, including participant observation, interviews and focus group discussions.

Setting Three hospitals in the Netherlands.

Participants Children with diabetes type 1, between 8 and 12 years ($n = 30$), parents ($n = 22$) and medical professionals ($n = 16$).

Results Children do not simply accept the recurrent health education from medical professionals. Instead, they attribute their own personal meaning to their disease and treatment. Drawing from their years of experience with the disease and health care and the image of a passive and vulnerable child, they actively find ways to balance personal goals with medically defined goals.

Conclusion Efforts to facilitate child participation should be based on insights into the ways in which children enact agency in the clinical encounter. Our data show that children already participate in health care and that their enactment of agency is based on a practical logic. Understanding of children's current participation and agency is needed to more successfully attune their treatment to their daily lives with diabetes. This is crucial for the success of treatment and the well-being of children.

Introduction

Conceptualization of children as 'vulnerable', 'incompetent' and 'passive recipients of care' has been challenged by social scientists for decades but still dominate medical practice.[1] The rights of children to participate have been established by the United Nations' Convention on the

Rights of the Child (1989), and many countries have additional national policies to support these rights. Nevertheless, scholars generally consider that children are not well informed in hospitals and face many barriers to participation in decision-making processes.[2–9] Based on a study of the status of children's rights in 15 hospitals of 14 Western countries, Simonelli and Guerreiro[10] concluded that the child's right to participate is violated in most hospitals.

This, however, does not mean that children do not participate at all in clinical encounters. On the contrary, as researchers have shown in the past,[11,12] children are social actors who give their own meaning and direction to their lives, even under the most coercive circumstances.[13–15] There has been little research on how children interact and co-construct the conversation, attribute meaning and negotiate treatment rules in clinical settings. This article aims to show how children with diabetes enact agency in clinical encounters and the resources which they have at their disposal. Based on this example, the article identifies lessons for improving health-care practices for children and facilitating their right to participate.

The case of children with diabetes is particularly interesting because the most of their treatment is not undertaken by medical professionals in hospital, but by patients themselves in their own daily lives. Children with diabetes inject themselves with insulin, measure their blood sugar levels, observe and interpret their bodily status and determine what type of action is needed. The treatment tasks they fulfil require considerable skill. Children themselves call this 'work', thereby framing their lived competence as analogous to that of their doctor.[16] Given the skills required, it might be expected that medical professionals and parents would consider children as knowledgeable partners and experts in how to cope with diabetes in their own everyday life, rather than as vulnerable and in need of protection. Nevertheless, children complain of being 'treated as children', by which they mean not being invited and valued as knowledgeable conversation partners. This article demonstrates how children with diabetes make creative use of resources to make themselves heard by adults and to accomplish personal goals.

Method and theoretical framework

The material for the case study was collected during the first author's intensive, 4-year ethnographic doctoral study of children with diabetes in the Netherlands. The case study involved participatory action research in which the children were co-researchers. Children with diabetes type 1, aged 8–12 years and identified at the diabetes outpatient clinic of three Dutch hospitals, were invited to define the core problem and develop an intervention with researchers. The children then evaluated this intervention with children with diabetes from two other hospitals, both located in a provincial town in the north of the Netherlands. The primary researcher (CD) facilitated and evaluated this intervention. Simultaneously, as ethnographer, she gained insights into the experiences, practical logic and life worlds of children, and the power and dependency relations between children, parents and medical professionals. Practical logic comprises a logic that is grown in practice and sometimes leads people to simply do what they do.[23] Research activities included a literature study; 6 months of participatory observation in the three diabetes outpatient clinics; semi-structured interviews with children ($n = 30$), parents ($n = 22$) and medical professionals ($n = 16$); focus group discussions; and informal working sessions in which two interventions were developed with the children, namely a book and a rap (chanted rhyming lyrics).

This article mainly draws on interviews with children, participant observation in the clinical setting and informal conversations with the children. Observing participation patterns in the health-care system and integrating these into the research provided insights into the ideology and practice of participation. The medical ethical committees of all three hospitals gave their approval to the project. Parents and children provided informed consent: they were informed about the project and were aware that their participation was voluntary and that they could opt out at any time.

For analysis of the power and dependency relations between children and adults in diabetes health care, we adopted a Foucauldian perspective on power. In this approach, power is not intrinsic to social position (child, parent and medical staff) but is rather a relational phenomenon that can be described as a localized, strategic, invisible and diffuse.[17–19] We were particularly interested in the strategies that children use to realize their personal goals, namely their agency. There has been longstanding debate among scholars on how to define agency.[20,21] According to Giddens[15] and Bourdieu and Wacquant[22], agency is not equivalent to the exercise of authentic choice or self-directed action but rather should be understood as complex and multidimensional, inclusive of emotions and practical logic. This project was able to take this complexity into account by combining formal research activities (interviews and focus group discussions) with many informal activities involved during development of the interventions, such as workshops, meals, play activities and travelling together to meetings. These informal moments, often taking place outside the hospital, provided considerable insights into the perspectives and practical logic of the children involved.

Results

First, children's responses to doctors' advice on their disease and treatment are outlined. Second, the possibilities for children to demonstrate agency are considered. Finally, the main resources from which they derive agency are presented.

Clinical encounters

The interviews and observations during clinical interactions demonstrated that medical professionals are strongly committed and genuinely concerned to improve the health and well-being of children with diabetes. For example, medical professionals are on call at night and in the weekends, and some even have sleepless nights about children that do not do well, having visions of amputations and blindness in young adulthood. Almost all medical professionals complained about children's non-compliance with the treatment regime: 'I am just about on top of it, but it doesn't work', 'I can't get my head around it', 'I can now [referring to a new patient] cram everything in, later their system is closed, and I won't be able to put something [guidelines] in'.

The metaphors in these statements illustrate both the simultaneous power and powerlessness of the medical professionals. They emphasize professionals as active agents and represent the child as an empty box that has to be filled with medical information. Children, however, appraise and act upon incoming information within the context of what they already know and in relation to their personal needs and ideas. As Iben explained:

> When somebody says: 'You have to do sport everyday', but I don't like to hurry every day, or I hate sport, then probably I am not going to do it, or I will forget it... Then I don't listen.

Medical professionals frequently refer to children's lack of knowledge. For some children and parents, the level of abstraction of the medical information was indeed too high to understand. Other children, however, could reproduce the medical story without any problem but, even after years of health education, make their own interpretation and chose to ignore the medical story. This is illustrated by Saïd's and Jamna's respective answers to questions about the cause of their diabetes:

> So it is hereditary. You can also get it when you get very scared or often angry. I don't know which of the two is the case for me.

> Maybe I have eaten something wrong in the past... I don't know. The doctor thinks something else.

Both acknowledge the medical discourse in addition to their own explanation, and they are not disconcerted by the fact that the doctor is of a different opinion. This cannot be put down to ignorance, pathology or mental limitations of the children: Saïd, for example, had just received the maximum score in the national educational performance test for children aged 11 years about to enter secondary school.

Children not only have their own ideas about the need to adhere to treatment rules and the origin of the disease but also what constitutes 'good' blood sugar levels. For example, Bart and Fatita are aware that medical professionals strive for a blood sugar level between four and ten, but they themselves consider a result below four far too low: 'Then you still feel shaky, and then you have to eat something'. Ghalid, on the other hand, is happy when his level is below four: 'Yeah, I like that, then I can eat extra'. Sixteen he considers good too: 'Normally that is high, but I consider it good, then I say that I won't need an extra injection'. Medical professionals' target blood sugar levels are generally determined by the risk of complications in the long run (e.g. blindness, amputations and renal failure), while children determine levels on the basis of how they feel and the implications for what they can do and eat. This is remarkable because, by taking such an approach, children withstand the strong disciplinary power of ever-recurring health education and the classification of symptoms based on medically defined facts and relations.

Despite the fact that children often have their own opinions on the causes of the diseases and on blood sugar levels, observations demonstrate that they hardly ever openly question medical discourse and treatment rules in the clinical encounter. This was confirmed by children in interviews. The unequal power relationship, dependency and the controlling presence of a parent in the consultation room restrict direct and open confrontation with medical professionals. Instead, children choose silent resistance and non-compliance. For example, Nassar responds to the doctor's question as to why he *again* did not bring his blood sugar device to the consultation by saying it was an oversight: 'Must have fallen next to my bag when I wanted to put it inside'. Non-verbal signs of resistance, such as demonstratively sitting in a slouched position, watching the clock, closing the zipper of their jacket and answering questions with a jaded 'Yes', 'No' or 'OK', can be read as silent protest. As many children explained, after years of experience, they are fully aware of the questions to expect and the 'appropriate' answers.

Exerting agency away from the clinical gaze

In contrast to the situation outlined above in the clinical setting, we observed that children have more possibilities to enact their agency outside the hospital. Ghalid is visibly at ease when he explains to the researcher (CD): 'I can't eat exactly on time anyway, and I can also inject later. I do that often, then I eat first before I inject. You don't notice the difference'. When asked why he ignores medical advice to inject before dinner, he explains that his family starts eating without him if he injects before dinner. By the time he is ready to eat, they have finished and his food is cold. When the researcher suggests that he could start injecting earlier, he answers that he does not like to do that. It would mean that he needs to inject quite some time before dinner which implies he needs to watch the clock, needs to know what his mother will cook and at what time she will be ready. Taking all this into consideration would make it impossible to fully enjoy playing football with his friends.

The extent to which children find or create opportunities to enact agency is underestimated not only because their capabilities are underestimated but also because they spend a lot of time out of the sight of adults, in their own room, at school, at friends' houses or playing outdoors. Moreover, many parents work or have other responsibilities. As the researcher noted in her diary:

> I picked up Zayna in my car for a work meeting. While getting into the car, she told me that she was alone at home. Her mother was at the health centre with the baby, grandma was at school and her brother as well.... I barely had time to say

> anything when she continued to tell me that she had secretly eaten sweets. Her mother had forgotten to take the key of the box of sweets with her and the box was open. She told me that she had eaten chocolate and, to compensate, had vacuumed the sitting room.

The example of Zayna shows the thoughtful nature of some strategies. With vacuuming, she regulated her blood sugar by physical activity and also pleased her mother by being a good daughter. Almost 8 years old, Iben explained in an interview that she does not receive many sweets from her mother and, to get around this, she now and then fakes a 'hypo' (too low blood sugar level). She provided a detailed and accurate explanation as to how she does this and why she uses a strategy that invokes the fear of her mother has for a possible hypoglycaemic coma.

Children's enactment of agency, however, is not always as strategic as the above examples suggest. Sometimes agency is simply an expression of resistance against the continuous discipline that the treatment regime imposes. In response to the question as to whether or not she always checks her blood sugar before injecting insulin, Marijke answered, 'Yes, but sometimes I do it in reverse order. I don't like to do it always, so sometimes I do it reversed'.[23] This example and the example of Ghalid, who often injects his insulin after dinner, represent a practical logic rather than a preconceived plan. The deliberate silence of many children in the consultation room can also be seen as a form of practical logic. In their communication with adults, many children felt as though their descriptions of experiences fall on deaf ears and are not taken seriously.

Sources of agency

As the above examples show, children stick to their own meanings and demonstrate creativity and resourcefulness, enabling them to protect personal goals and preventing them from being overruled by one-sided, pre-defined medical goals, although they do acknowledge that these goals save lives. Some children are cognitively and verbally skilled, as Aischa (12 years) illustrates in her reflections on the future:

> I do know what can happen. You can become blind, severe things can happen, but that is when you are always high [have a high blood sugar level, CD] and that is not the case... Well, then they speak about 10 years... In these 10 years, so much can happen and maybe we even won't have diabetes anymore because they have found a medicine for it...

By referring to the potential of new developments, she directly refers to the promise of medical science. She has learned about this in the consultation room but also from the many stories and advertisements in magazines on diabetes, as well as the internet and TV. Moreover, she explains that statistics do not say anything about her as an individual: 'Those people who got complications are different people, they lived in another time, with other resources and treatment options'. In her reflection, she strategically uses the claims of the dominant discourse. When it suits her, she adopts it (the potential of medicine), but when it does not suit her (statistics about complications), she doubts and refutes it. She plays with the power of the medical system that defines universal diseases and claims the ability to predict her personal future.

For less verbally skilled children, especially young ones, the body itself is an important source of agency. Confronted with an examination or blood collection, they sometimes literally hide behind their mothers, seeking refuge under the desk or resist medical examination or treatment by screaming, crying and kicking. Ivan, a 3-year-old boy with a cognitive impairment, dictated the terms of a consultation by demonstratively closing his jacket time and again and by walking to the door. When this did not result in the termination of the conversation, he walked back to his mother to close her jacket too, walked back to the door and kept his hand on the door handle until she came. Due to the inconvenience he had created, he did not have to wait long because his mother and the nurse decided to continue the consultation another time. This example illustrates that age, individual abilities, wishes and experiences, as well as the specific context and structure in which an interaction takes place, determine the expression of agency[24], but not necessarily the effect it has.

Our analysis of these and many other examples of children's agency in the management of diabetes shows that, in addition to their own personal skills and capabilities, they derive agency from two sources: (i) being a child and (ii) being chronically ill.

(i) Being a child

Some activities, acts or expressions of emotions are reserved for children and are less accessible for adults. While their verbal capabilities may be more limited, this is compensated by their body language.[25] Children can, in contrast to adults, hide behind the backs of their mothers, demonstratively keep silent, limit their answer to a jaded 'Yes', 'No' or 'OK', look the other way and with shouting, kicking or a noisy game disturb the conversation or treatment, without being considered rude. This represents what De Swaan describes as the power of the weak to obstruct.[26]

Moreover, children can also influence their environment because adults' reactions to children are steered by powerful images that stress children's dependency, vulnerability, innocence and lack of power.[14,25] Their assumed helplessness and associated suffering place children in situations where they are cared for and remain unaffected by blame. It is acceptable for children to be labelled as difficult, annoying or oversensitive. As White[27] illustrates, they are rarely held responsible from a medical point of view. Children's unruly behaviour is explained by projecting responsibility upon the parents, such as when parents are blamed for 'not being strict enough'. Or their behaviour is rationalized within the context of the child's illness: 'it's the disease, the type of diabetes' or it is allocated to the realms of puberty and peer or school pressures. Children's reflexive awareness of these perceptions and of how they can manipulate them increases their opportunity for exercising agency.

(ii) Having a chronic illness

Disease offers an important basis from which to respond and act because people, especially those with chronic illness, have a long and intensive experience of their disease, their body and the health-care system. Children with diabetes have learned by experience that the metabolic body is difficult to control and cannot be allocated to medically defined boxes. They all gave examples of advice that worked for one person, but not for the other, and of moments when nothing seemed to work. They are intimately acquainted with the imperfections and limitations of medical thinking and acting. The lived and empirically tested knowledge of the children undermines the idea of a medically defined truth, or at least puts it into a broader perspective. In addition, children with diabetes have often become wise through, sometimes bitter, experience, and they have learned when and how to confront, to challenge and to persuade. Many of them have learned to keep silent in the consultation room. In addition, they have personal goals and determine for themselves how to act outside the hospital.

Children living with diabetes skilfully manage their lives and all the rigorous demands of diabetes beyond the gaze of medical professionals. As the example of Ghalid demonstrates, they not only interpret treatment according to their own perspective but they also act on this. Although technical assessments can show that the metabolic balance is disturbed, medical devices and professionals often cannot explain why the blood sugar level of a particular child is low, high or unstable. This explanation can, in many cases, only be given by child itself. Professionals need children's information to determine whether to adjust the treatment and to decide whether a new treatment strategy might work. This 'convenient' dependency protects children with diabetes from becoming objectified and ensures that the conversation cannot become too unilateral and dominated by professionals. Indeed, such domination would lead to a situation, as has been experienced by many medical professionals, where children do not want to share essential information and in which the relationship between children and professionals deteriorates.

Discussion

The analysis of how children enact agency and the resources they have at their disposal clearly indicates that social processes, within and outside the medical arena, are not only determined by impregnable institutional structures or medical regimes of professionals but that children influence the interactions in the consultation room.

The children in our study developed strategies that enabled them to stick to and to act on their own ideas, demonstrative of their expertise in living with this demanding disease. They have learned to refrain from openly acting against existing power relationships within the consultation room (in terms of Ortner 'agency of power') and to focus on goals that they want to protect or accomplish (in terms of Ortner 'agency of projects'). The primary focus of the children is on how to integrate the demanding treatment in their daily lives and the wish to be 'normal'. This focus on having a normal life has also been found in other studies of chronic illness.[28–30]

Despite the fact that many children did not feel invited to actively participate in consultations with medical professionals or lacked the courage to speak freely when they were invited, they found creative ways to justify their feelings, experiences and personal goals in life. The most powerful resource at their disposal was their tacit knowledge, based on their years of experience and insights developed outside the hospital. While open obstruction was not encountered in the research, children commonly acquiesced in the consultation room while doing exactly what they considered important themselves.

The way in which children enact agency has limitations for all stakeholders. Professionals are not sufficiently aware of the challenges children with diabetes confront in their daily lives and, as a consequence, cannot fine-tune the treatment and education to the life of the child (cf.[31]). Moreover, the avoidance behaviour of children means that their tacit knowledge is not available and that the goals and implementation of treatment are not questioned, nor can their knowledge be of help to other patients. Medical professionals do not have sufficient insights into nor sufficient interest in children's daily lives and experiences and the challenges they face. There needs to be more interaction with children as knowledgeable social actors so that they are willing to openly share their personal experiences within the consultation room. Improved understanding of their practical logic, as a result of a real dialogue, is crucial for the success of their treatment and well-being. Although difficult to arrange, meeting children outside the walls of the hospital is helpful to developing understanding of how medical treatment impacts and relates to the daily lives of children.

The current discourse of patient and child participation is based on an understanding that children need to be brought into the system. Our results show that they are already insiders. Children are not outsiders that need to be included or invited to participate, but active agents in the management of their illness, both in the context of their daily lives and in the consultation room. Having made this point, we do not want to suggest that child participation does not need our support and improvement. On the contrary, we argue that rearranging social circumstances to improve participation would mean that the now often hidden or misunderstood agency of children could be more openly exercised and consequently easier to recognize. If we pay attention to *how* children already participate – how they confront, change and reinvent treatment rules, and with what purpose – we will obtain important insights into the life worlds of children with diabetes, into their aspirations, dilemmas and choices. These insights could be employed to question and improve health care and create more reflexive practices. If we are not willing to look at what children already disclose, it might be useless to invest in creating better opportunities for children's participation.[6] In fact, if we think that children can only participate when they are invited and facilitated by adults or in specially designed projects, we might even be contributing to the reification of the child as passive recipient of care.

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