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Embodying illness and managing the uncertainty

Entering a career of a person having a chronic illness implies the management of several situations of uncertainty. Through two pilot ethnographic researches carried on in Northern Italy and France among children affected by a type 1 diabetes, we have analysed how somatic instability due to the children's growing up is intertwined with the instability of the manifestations of the illness. Managing this “new body”, therapeutic objects and technologies implies a reconfiguration of self, a path entangled with pitfalls and fruitful infringements. In this article, we put forward the concept of “*savoir-faire*” as more pertinent to express a bodily experience, embedded in material culture and the ability to cope with highly sensitive and unstable situations.

Key words: children, chronic illness, uncertainty, embodiment, medical anthropology, competence

The child has long been considered as a “body”, which adults, in their different roles, treat or care for (James 1993). The reduction of a child to a “physical being” in care situations is part of a wider representation of childhood as a period characterized by immaturity, unawareness and dependency. In this approach, the child capacity to progress and mature is largely due to the transmission function of adults in the socialization process. Since the 1980's the sociology of childhood and childhood studies have promoted a different view of the child. The new model sees children as social actors who play an active role in the construction, interpretation and reformulation of the social world (Alanen 1988; Corsaro 1997; Mayall 1994; James, Jenks, Prout 1998; Sirota 2006). Children are viewed as “present beings” rather as “becoming” (Lee 2001) and the generational order is negotiated and relational (Alanen 2010). This interpretative perspective has been applied in the

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field of health and illness. The works of Blueblond-Langner (1978), Prout (1989), Christensen (1993), Mayall (1996), have given new meanings to children's competences: these are seen less in terms of the psychological-cognitive skills that mark an individual's development than in terms of the relational skills the child shows in immediate, life-in-the present situations. According to Hutchby and Moran Ellis, children's competences are "a constantly negotiated dynamic, a phenomenon which is stabilized, to a greater or lesser degree, in and through the interaction between human actors and the material and cultural resources which are available" (Hutchby & Moran Ellis 1998: 15). As Favretto and Zaltron (2013) show, competences are acquired and further processed in day-to-day practice and they are more complex and focused where relational situations are involved. Even if these competences are invisible to adults (Tates & Meeuwesen 2001), children display the ability to perceive and report discomfort of physical and psychological conditions through communication modes and codes they acquired in previous experience of illness and that caregivers – parents, close adults, teachers, peers – understand.

As the "new sociology of childhood" highlighted the role of children as actors and their interdependence with adults, this idea of competence is deeply intertwined with the concept of agency. However, this irenic, optimistic view of agency, which was necessary to establish a new vision of a child, sometimes neglects the difficulties children have in coping with chronic illness. As medical anthropology has shown, chronic or long-term illness throws the very frameworks through which we apprehend the world into disarray, and so addressing it requires particular understanding (Bury 1982; Kleinman 1988; Greenhalgh 2001; Eugeni 2011). Coping with it means to routinely scan minute bodily process: "people who have always been bodies have distinctive problems continuing to be the same sort of bodies they have been" (Frank 1995: 27). Long lasting or chronic illness disrupts the ordinary perception of time, body, suffering, and what and Good calls, following Alfred Schutz, "the world of experience" (1994).

Managing this "new body", therapeutic objects and technologies imply a re-configuration of self, a path full of hesitations. In this article we focus on the uncertainties the child experiences when coping with chronic illness, how the acquisition of competences is entangled with pitfalls, failings and fruitful infringements (Brougère 2009) that demand the actor's reflexivity. Through a pilot research in a day hospital in Trento (Northern Italy) based on 26 interviews with young people, 16 with children aged 7–14, suffering from Type 1 diabetes, and a fieldwork in a holiday camp organized by the association "Aide aux Jeunes Diabétiques" (AJD)³, we will particularly stress the concept of *savoir-faire* as an embodiment of

³ This fieldwork has been held in the holiday camp at Gouville sur Mer, managed by 'Aide aux Jeunes Diabétiques' (AJD), a French organization that superintend various activities for children recently diagnosed with Type 1 diabetes and their parents in order to support them in the daily

material culture, techniques and social situations, which are a part of a process of subjectivism. Uncertainties and hesitations are a central dimension of *savoir-faire*, as far as they mobilize the criticism of the actor⁴.

From feelings into symptoms, and from symptoms into naturalized clues

The pilot research took place in 2011 in a diabetes day hospital in Trento, where the young patients undergo medical tests every three months to measure their levels of glycosylated haemoglobin, blood glucose, cholesterol and glycosuria, as well as their weight and size⁵. They meet with a diabetes specialist to discuss the test results and adjust their insulin dosage together⁶. A chronic disease such as diabetes affects children deeply as it involves a transformation of daily routines, social relations and body-related activities (Damião & Pinto 2007). “Beginning a career” in diabetes, in the sense of Howard Becker (1963), heightens the feeling of uncertainty: as for children, it takes the form of developing strategies in domesticating instability. The interviews show that the first step in this career is the gradual construction of knowledge concerning bodily signs and their interpretation. A major element of uncertainty is that of the translation of the sign into a symptom of hypo- or hyperglycaemia.

burden of chronic illness and to increase children’s degree of autonomy in the self-administration of treatment. The anthropologist was not involved as expert or parent, but as a researcher carrying on participant observation in stages with children aged 4–12 who recently were diagnosed with diabetes mellitus type 1 and their parents. 8 interviews with parents and 1 with a child aged 12 were conducted. Semi-structured interviews were aimed at understanding the onset of disease, the first period of life with a chronic disease and adjustments of family life; how peers and school mates and teachers act toward diabetic child; how a child feels the life adjustments due to disease.

⁴ In this contribution, we will use the French word *savoir-faire* and *savoir-être*, instead of the English translations “knowing-how-to-act” and “knowing-how-to-be”, which don’t cover the exact same dimensions of the French terms.

⁵ Type 1 diabetes is a form of disease in which not enough insulin is produced. The lack of insulin results in high blood sugar levels. The classical symptoms are frequent urination, increased thirst, increased hunger, and weight loss. The cause of type 1 diabetes is unknown. However, it is believed to involve a combination of genetic and environmental factors. The underlying mechanism involves an autoimmune destruction of the insulin-producing beta cells in the pancreas. There is no known way to prevent type 1 diabetes. Treatment with insulin is typically required for survival. Insulin therapy is usually given by injection just under the skin but can also be delivered by an insulin pump. A diabetic diet and exercise are an important part of management (for further information, cf. Daneman 2006).

⁶ One of the crucial questions is the difference between the technical devices, but we will not develop this question here, it deserves a long development impossible to tackle in the limits given to this contribution.

A correct decoding is essential here, in order to speed up the necessary measurements and adjustments. In the initial stages of diabetes, a period which may take a few years, many children have trouble recognizing the signs of hypo- or hyperglycaemia, and are in danger of fainting or having to go to the emergency room. A specific technology-mediated competence proves necessary to translate the feeling into a symptom. In the case of 11-year-old Michael (diabetic since age seven):

Q: And if I say “hypoglycaemia,” what do you think of first?

Michael: Well, that the blood sugar goes down?

Q: Yes!!

Michael: Well, I have to eat. First I do the test and depending on the result, I drink a glass of juice or I eat some crackers, etc.

Q: Ah, good! So, you always do the test?

Michael: Yes!

D: And how do you feel?

Michael: I feel weak... Mmm... I mean you feel weak, sometimes you don't feel too good either, your head hurts, or your tummy so you do the test⁷.

In Michael's statement the physical sensation has to be verified by the test, in order to confirm a change in blood sugar level. By incorporating the technical object and the data it provides, 'I feel' becomes 'I know'. The elaboration of such competence can take years, while diabetic children are incited to take care of themselves as soon as possible and improve in translating the experience of medical terms and cure actions. Here is Angelica, whose diabetes was detected when she was five:

Angelica: I don't like the shots, and most of all, I don't like going to hospital when I'm sick.

Q: Ah, because you have been hospitalized since your illness began?

Angelica's Father (who accompanies Angelica and is present during the interview): Yes!

Angelica: Yes, I've fainted five times!

Q: Always because of the hypoglycaemia?

Angelica's Father: Because of hypoglycaemia!

Angelica: Three times at school and twice at home!

Angelica's Father: The two times at night...

Q: But you don't feel them coming at all? You don't feel... I don't know, for instance, I myself, I start to tremble, I can't see clearly, don't you? Nothing?

Angelica: (shakes her head to say no)

⁷ At the Trento Diabetic Day hospital unstructured interviews were conducted in a fieldwork in order to obtain a master in medical anthropology at the University of Ca' Foscari, Venice: this explains the dialogical presentation of quotations. The interviewer – Marcella Calavin – had herself a type 1 diabetes since she was 8. This condition was useful in sharing experiences with children and teenagers interviewed.

The codified perception of symptoms is an essential moment in the incorporation of the illness and the somatic attention it requires.

Q: But what did the doctor say about the fact that you don't feel your hypoglycaemia?
 Angelica's Father: When she was diagnosed with diabetes, she was not in Italy but in Poland. In Poland people are not informed, but in other ways they are far ahead. For instance the insulin pump, they've already given that to children... Here why [the doctor] told me that they send children with hypoglycaemia to the hospital, they keep you for one, two or three weeks, until the child can understand [what's going on]. Whereas in Poland they taught her how to do it with the pen [the insulin pen], how to use the glucometer, the insulin, and goodbye!

Q: So they didn't ask the basic questions, like how to learn to feel one's body...

How to enact a *savoir-faire* that deals with distinguishing physical signs through a medium that implies neither inter-generational nor inter-peer transmission – neither a community of practices, nor the reduction to a technical act? It is interesting to remark that these learning difficulties emerge as the child is solicited by an interviewer who has herself been diagnosed as a child with Type 1 diabetes. Once the interview is over, Angelica's father asks Marcella, the interviewer, how she "feels" her bouts of hypoglycaemia, how she has learned to handle them, and most of all how she manages to wake up at night and anticipate any dangerous consequences. Marcella can't help him: "it's something I feel – she says – it's spontaneous and I can't explain it, I wake up". This particular way of incorporating a disease thus refers to a form of competence reduced to a "natural, spontaneous". With the time going, such *savoir-faire* abandons the codifications taught and shared by the exterior world through the language of symptoms, and becomes a *savoir-être*, a knowing-how-to-be. The identification of signs results in a reconfiguration of the body, until it becomes a naturalized dimension. Alessandro, aged 14, who has had diabetes since he was 7, expresses this reconfiguration of children's relation to their bodies through the idea of self-control:

Q: Your diabetes began quite a few years ago. Has your way of living (with) the disease changed?

Alessandro: Now, yes, it's easier! No more self-control...

Q: You manage better. Even with food?

Alessandro: A bit better, yes, yes.

Q: And with the insulin? Are you better at telling how many units you need?

Alessandro: Yes, Yes, that's for sure! Before, I did not know how many doses I should take... Now I know, I know the doses, how to correct them...

Recognizing a symptom implies being able to distinguish between the physical quirks that are proper to one's age, those that are linked to physiological conditions

(fatigue, hunger) and those that are caused by the disease. For children, being able to detect the illness clues measures the process of growing up as developing in the right way (so, “to be normal”). As for the symptoms, they need decoding as they highlight the burning questions of norm and normality. To put it in the words of a 7-year-old Alessia, “to be right” is what defines this need for stability.

Q: What is the hardest part of having diabetes?

Alessia: To be up and down... I like to be right, because alternating between up and down... I like to be right [in the middle] because as my mom says, if you're down, you have 300 and if you're up it's not good either

Q: Are you afraid of what might happen during those ups and downs of your glycaemia?

Alessia: well of course!

Q: But now you're OK?

Alessia: Yeah, yea, I'm good... sometimes I go very far down...

Q: Yes, that happens. And your (glycated) haemoglobin, how is that?

Alessia: Yes, well, after a birthday I had 549!

Q: You ate some of the birthday cake?

Alessia: Mmh... (...)

As one can imagine, the reference to food is very frequently made. The interviewed children are at an age when food plays fundamental role in their self-assertion. At the end of childhood, eating habits and food are perceived as a controversial territory – so both a cause for pleasure and social interaction, and a testing ground for discipline and restriction: as a consequence, some food is seen as an insidious enemy – between the unpredictable damage and the pleasing transgression. The group moments of binging on everything that is considered to be bad for one's health (Nutella, cookies, pizza, sodas, etc.) are replaced by private moments of purging through water, yogurts and fruit (Diasio 2010). Children with diabetes cannot afford such swinging between self-control and letting go, though the new relations they build with food prove relevant for their passing from one age to the next one. The importance of “this self-exerted self-control or self-constructed self-knowledge” in the sense of Foucault (1988) is especially visible when children are out in the public sphere and in the strategies they invent to manage the unforeseen.

Not all the children have trouble in recognizing bodily signs: this is the case of Paul (age 7), who we met in the second field, in AJD's camp at Gouville sur Mer (Brittany, North France) in October 2014. His mother Béatrice says:

B.: He was immediately able to express what his body felt. He was immediately able to verbalize what he felt, immediately! He is able to diagnose, the signs are always the same: headache, or stomach ache... that's it! These are his own signs, and every time we check his glycaemia and there it is. This reassures me because he soon

realizes there is a problem (...) this has happened since he left the hospital, he has always succeeded in it.

In some cases, children are able to announce in advance the measurement of glycaemia, as Iris (age 6, who has had diabetes since she was 5) in the words of her mother Linde:

L.: Now she feels it, she can even tell us the measure: “I think I’ve got 45”, and she’s got 47! “Mom, I think I’ve got 50”, and she’s got 52. Not always, but now, when she tells me she’s not fine, she’s never wrong. Sometimes she can’t feel it, when it’s too low, sometimes she is 30 and I ask her “How are you?” she answers “When you ask me, maybe it hurts here”. She feels the low ones less than the others. But we often ask her about it.

In diabetes, “self-awareness is at least as important as measuring” (Mol and Law 2004: 47). Glycaemia is something children “have”: hyper- or hypo-glycaemia are “the body as something they are” (Mol and Law 2004: 57), a state in which children find themselves, and which is characterized by its instability. The stress on children’s awareness encounters the children’s desire of autonomy. Lucie (12) states:

Q: Are you able to administer the therapy yourself?

L: Yes.

Q: And are you using the insulin pump or the injections?

L: I’m using the injections, but during this holiday Stéphane [the AJD doctor] said it would be better to try the insulin pump, and I want to try it, to be more free.

A chronic illness places the child between two opposing worlds, between health and sickness, between ordinary time and moments of emergency and crisis. As theorized by Hintermeyer (2011), it constitutes a meta-illness that produces a range of uncertainties and makes it necessary to cope with the body’s instability. Temporality, uncertainty, stabilization and domestication of the body are fundamental dimension to understand children’s experience. Such factors contribute thus to both incorporating the illness and making one’s competence visible, as well as “visible in whose eyes”.

Intimate body, public body

The second important aspect of the management of uncertainty is linked to a dialogical relationship between the intimate and the public body, which requires a twofold competence. The first competence concerns the acts that are necessary

to control insulin, and which are carried out not only at home and among intimate relations, but can also happen in all the public places where children dwell: school, the school canteen, and the places where they live their social life and spend their leisure time. In order to make sure that everyone understands what they are doing, and to inform others of a possible need for assistance, the children (and their parents) have to make their condition known to other adults (for instance to teachers or other school staff) and, more selectively, on the child's cue, to friends and classmates. The second competence involves the strategies deployed to measure and administer insulin at the right moment without being seen by anyone. Here is Giada's testimony (she's seven):

Q: And do you talk about it to your girlfriends, have you told them you have diabetes?

Giada: Yes, I've explained it to them!

Q: And did they understand?

Giada: ...A little... you know...!

Q: What do you think they did not understand?

Giada: The equipment to... to measure! Eh, but I think that they saw me because I do it in class.

Q: And they saw you give yourself the shot?

Giada: Yes!

Q: And what do they say about this, that you have to give yourself a shot?

Giada: Eh... one of my classmates has to close his eyes because he's scared, and my friends ask me "does it hurt?". They ask me if the shot hurts!

D: So if you tell them it's going down, you can leave the classroom?

Giada: Yes because my mom has made them a table to keep in the classroom. When I'm at 40, I have to eat this, I have to eat that, when it's too high I have to do this or that...

Q: And your teachers, are they OK, are they nice about it?

Giada: Yes! And my teacher does not want to watch when I give myself a shot in class, like my friend!

We can observe here how "therapy is a symbolic boundary marker" (Prout & Christensen 1996) that allows a child to establish her superiority over the other children, and we see how, in this particular case, this is accompanied by claims concerning age and gender (the fact that she's not afraid of the shots is contrasted by the behaviour of the boy and of the teacher). Moreover, as *savoir-faire* is expressed here in the school environment, it also implies a redistribution of competences between adults and children. Furthermore, the technical tools have an impact on the subject who uses them: the use of the insulin pump or the shots modify children's experience and perception of their body, and brings along different actions on the self, by the self, thus creating subjects who "are not cut out of the same wood" (Warnier 1999).

Or there is Sylvia, a 12-year-old, who suffers from diabetes since age 8, and who combines in her testimony both the ease (at least that's how she tells it) in public places, as well as the quick recognition of the feelings, in a discourse that is all set in the first person singular and does not evoke the test:

Q: So you have learned to give yourself the shot all by yourself, even the insulin shot, and even when you're not at home?

Silvia: Yes, yes.

Q: And do you talk to your friends about it? In school?

Silvia: Yes, but it's as if I had nothing, I mean, it's not a problem, if I feel weak, they help me and they don't laugh at me.

Q: Great! And they help you when you're hypoglycaemic?

Silvia: Yes, yes...

Q: Good! And the teachers? Do they help you?

Silvia: Yes, yes, sometimes when I feel weak, they let me go outside, or they come with me, sometimes they stay with me.

Q: Good... and when I say "hypoglycaemia" what do you think about first?

Silvia: That it's going down! And the headache... I feel weak, I have to sit down because I can't stand up anymore...

Other strategies are also discussed: the large bag which girls carry to hide the technical apparatus from their peers, the choice of wearing trousers instead of skirts, because the zipper allows you to inject insulin into the belly rapidly and without being seen (even under the table!) and discreetly going to the bathroom; these are all ways in which uncertainty is managed. These tactics are aimed to avoid stigma in a Goffmanian sense. In fact, children claim that diabetes doesn't change their lives: "Besides having knowledge and skills, young children can be competent at making choices, managing differences, and being 'normal'", and social competences "tend to be 'just to get on with life' and to have fun with friends" (Sutcliff, Alderson, Curtis 2004: 91). At the same time, children and teenagers feel that they are constantly under the observation of others. Intimate body is a public one too: for example the alarm of pump batteries can ring in the class, and sometimes children having this disease are in the spotlight. As a 6-year-old child's mother says: "When she began the after-school activities, it was the big show". The new technologies for insulin administration are also conceived to avoid this stigma connected to former types, as multiples injection. Nevertheless, all these tactics, which allow the subjects to control unpredictable situations, require a great social competence which consists of evaluating whether and what the situation allows one to do, including the choice of whom to talk to about the situation and how to manage the moment of "coming-out" about one's condition as a carrier of a chronic disease.

Savoir-faire as managing a new self in an unstable context

From 1980s on, anthropology knew a threefold turn: corporeal, sensitive and material. The rereading of Mauss (1934) and Merleau-Ponty (1945) led to the phenomenological idea that “we conceptualise through our bodies”, the “mindful body” analyzed by Margaret Lock and Nancy Scheper-Hugues (1987) demonstrated the emotional, social and political source of health and illness. Both the phenomenological approach of embodiment (Csordas 1994) and the concept of “incorporation” (Warnier 1999, Julien & Rosselin 2009), albeit very different in their paradigms, showed how techniques of the body and the production of knowledge, experience and representations are embedded in the material culture (Place 2000). The person embodies material culture through its motor activity, but, at the same time, artifacts and objects exert an action on the subject too and modify it. This entanglement produces different identifications according to social situation. This framework is central in a disease like type 1 diabetes. Because of the constraints it generates and the actions which it either limits or encourages, chronic illness gives rise to various forms of *savoir-faire* (knowing-how-to-act) which, once they are incorporated, transform the subject and become forms of *savoir-être* (knowing-how-to-be). As our interviews revealed, children are obliged to constantly deal with embodied technical devices, act as mediators with other social actors – medical staff, family, peers – and reappraise the self.

The French word *savoir-faire* puts the emphasis on sensitive intelligence, on the emotional, relational and expressive aspects subtending the construction of knowledge. It strengthens the central position of the body and sees body techniques as actions that are learned, passed on and efficiently supported by material objects. The Italian anthropologist Franco La Cecla writes about the “*saperci fare*” (“knowing-how-to-act-there”): the particle “*ci*” designates some indirect complements, as the complement of place; it describes a know-how-to-act in a given context, a competence taking into account the social situation. Acquiring such a *savoir-faire* takes time and calls for adjustments; it is a rough path “where you strike against the sharp edges of a reality that is not consonant with the actions of the body” (La Cecla 1996: 7). It leads us back to uncertainty and to time necessary to cope with. Sensitive experience resists language, twists it sometimes, and is rebuffed by language’s inability to put such experiences into words, concepts and medical advice⁸.

⁸ The heuristic value attributed to corporeality thus puts into question the highly successful, but far too sharp, distinction between “expert knowledge” and “profane knowledge” (Beck 1986; Giddens 1990, 1991). So, the concept of *savoir-faire* reinforces the complementarity of epistemologies that are often said to be in competition with each other. It overturns the opposition between the technical, official competences representing expert knowledge, and the practical competence based

Striking against things and embodying them, produce what La Cecla calls authenticity: it is a way of situating oneself in life, and of carrying life's imprint on one's body, and it is the opposite of spontaneity. Such *savoir-faire*, then, implies the acquisition of what Foucault, in the Vermont seminar, calls the "technologies of the self" (1988) and which he described as follows:

The procedures (...) which are proposed or prescribed to individuals in order to fix their identity, to maintain it or to transform it to a number of ends, thanks to the control the self exercises over the self, or the knowledge the self has of the self. In sum, the idea is to replace the imperative of the "know thyself" which seems so typical for our civilization in the vaster framework of the question, asked in a more or less explicit context, of "what to do with oneself?". Which work to carry out on oneself? How to "govern oneself" by carrying out actions where one is the object of these actions, the field to which they apply, the means by which they are carried out, or the subject that acts?" (Foucault 1989: 134)

The reference to Foucault is also relevant for another reason. The subject described by Foucault through the concept of technologies of the self, is not the rational Cartesian cogito, nor is it the sovereign "I" of contemporary sociology. It is a weak subject, a person who is "not master in his own house" (Warnier 2015), and who is subject in both Latin understandings of the word: subject of the verb, of the action – the sociological agent – and the subjected subject, caught in the web of the power and of the actions of others. In the Foucauldian approach, managing its subjectivity is defined in terms of government. Governing oneself does not refer to domination or to absolute freedom, nor does it refer to a total control of the self over the self. The idea of government presupposes a certain degree of freedom, but also a margin of uncertainty and influence. This theoretical framework may help to rethink the idea of agency, on which the concept of competence is based. Agency is not a property of the subject, something which one supposedly has and exercises. Agency is more a disposition to act which overturns the opposition between active and passive, it is a *possibility* to move through a network of human beings, materials, texts, and technologies on which it relies. The agent is no longer simply the author of the action, but is caught in a system of relations over which he or she has no complete control.

John L. Austin wrote a small text in 1956 called *A Plea for Excuses* which presents interesting elements that can help to further develop the idea of agency. For Austin, excuses allow us to define the actions as something we could excuse for.

on experience and used by non-specialists. Although the distinction between "real" wisdom and practical knowledge, and the asymmetric relations which it creates, are maintained by health professionals, the studies which have been carried out among children have helped to undermine it by showing how affective, relational and expressive aspects constitute competences and resources for children faced with disease.

Actions are something whose achievement might fail, and whose intention is never complete. For Austin, excuses show the vulnerability of human action, and the absence of a director behind the scenes. So, taking into account the failures and the difficulties is a central dimension of competence, it allows to apprehend the way in which the reflexivity of the actor is mobilized. In La Cecla's work, for instance, the concept of *savoir-faire* is explored in a number of situations and fields where there is a large amount of instability and uncertainty: sleeping in public places, courtship and seduction, learning gender-specific behaviour, family resemblances, where "knowing how to move lightly between the jutting corners and opportunities [of life] is a dance that is painfully learned" (p. 8).

Deepening the hesitations, uncertainty, and missed endeavors gives to *savoir-faire* its very dynamic dimension. It allows focusing on how competences evolve with the several identifications of the subject. Experiences change, life-stages and biographical transition succeed, bodies develop, techniques progress requiring new forms of embodiment, agents and context modify and relay. In the recent years, the technological development in treating Type 1 Diabetes has allowed a more varied and complex reading of both the body and personal competences. More varied, in that the results of its usage cannot be standardized; more complex, in that biomedical technology offers an ambiguous mediation (Lock & Nguyen 2010): it looks as a single device, yet it is an arena where manifold actors meet – such as ill children, parents, doctors, the welfare, medical technology industries and applications for the remote data monitoring.

Conclusions

Even if the "un-finished body" is a lifelong shared experience (Shilling 1983), bodily changes are, for children a source of uncertainty and a resource for constructing and negotiating identities (James 2000, Prout 2000).

Yet, chronic illness increases the feeling of uncertainty, requiring a special thoughtfulness in focussing and decoding a twofold range of signs: the bodily clues connected to illness, and the signs sent by the other bodies which are present in the relational context. Entering a career of a person having diabetes implies the management of several situations of uncertainty. The somatic instability due to the children's growing up, the instability of the manifestations of the illness, the instability of food habits – which are often threatened by attempts to rebel against the imposed diet – are intertwined and require a specific, refined and complex *savoir-faire*. It is a special ability to fine-tune one's knowledge of oneself, one's body and one's limits, and of what is allowed depending on the social situation children are in. That is what Csordas defines as a "somatic form of attention": "to

attend to a bodily sensation is not to attend to the body as an isolated object, but to attend to the body's situation in the world" (Csordas 1993: 139).

Embodying illness, for the young individuals having diabetes, means to be involved in a long process of subjectivism encompassing the internalisation of the biomedical model, the embodiment of technical acts, the ability to act upon oneself and upon one's social and material environment, reflexivity and critical attitude, following the hesitations, difficulties and missed endeavours. In this context, the term of "*savoir-faire*" seems wider than the idea of competence. Close to the Foucauldian concept of technologies of the self, it is dynamic, rooted in a sensible, bodily experience, embedded in a material culture, formulated to express the ability to cope with highly sensitive and unstable situations. Moreover, it stresses the conceptualisation of a moving self, caught in its several identifications according to the social circumstances. A chronic illness is a matter of management of uncertainty – whereas the mediation of technology devices introduces another variable in the field of competence: the polarization between suitability and unsuitability about the proper use of devices, so that their use has to become suitable as it were naturalized. Medical technologies 'feel' the body better, so that following their directions allows following the nature of both body and sickness, and the reframing of a changing self.

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