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# **‘Adolescents are reckless’: Representations at stake in the construction of the relationship of trust in paediatric diabetology**

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**Abstract:** Ten focus groups were held with adolescents living with diabetes, their parents, and health professionals in order to explore their needs in therapeutic education. The analysis showed that the relationship of trust is a central concern for a number of participants. Several adults were divided between a feeling of confidence inspired by the need to empower adolescents to cope with the chronic condition and a sense of distrust inspired by the idea of carelessness and irresponsibility thought to characterize adolescence. Adolescents, for their part, seemed relatively clear-sighted about how they can be perceived, and blamed adults for not trusting them. These findings emphasize the importance of considering the representations at stake in the dynamics of the therapeutic relationship in order to better understand the construction of the relational climate.

**Keywords:** trust, diabetes, adolescents, social representations, qualitative research

## Introduction

Therapeutic education aims to help people living with a chronic condition as well as family caregivers to manage their lives as well as possible, so they can maintain or improve their quality of life according to their own expectations and needs (WHO, 1998). This interventional field marks the transition from a paternalistic model in which the professional alone makes the decisions for treatment, to a deliberative model based on the construction of a climate of trust that promotes a sincere discussion of expectations and needs of each of the protagonists in therapeutic education (Perdriger and Michinov, 2015). Specifically, trust promotes the exchange of information and participation in decision-making in order to suggest treatment options that meet the person's expectations and lifestyles (Lee and Lin, 2011).

### *The literature on trust in therapeutic relationships*

The scientific literature shows that it is important to construct a relationship of trust in order to help adolescents become more autonomous in managing their chronic condition and effectively achieve the goals of therapeutic education. It has been shown that individuals who trust professionals are more satisfied with the care they receive (Lee and Lin, 2011; Platonova et al., 2008), have fewer symptoms associated with their chronic condition (Thom et al., 2002) and improve their quality of life (Lee and Lin, 2011; Préau et al., 2004). Part of these results could be explained by the fact that the relationship of trust contributes to the development of an individual's self-management skills. It turns out that this relational climate reinforces collaborative decision-making (Berrios-Rivera et al., 2006; Jones et al., 2012) as well as their sense of self-efficacy (Lee and Lin, 2009). This climate also encourages individuals with a chronic condition to more easily disclose personal information to professionals (Berrios-Rivera et al., 2006; Hall, 2005), which would help them to better understand their everyday life experiences and thus adapt treatments accordingly.

This literature focuses primarily on a therapeutic relationship between an adult with a chronic condition and a professional. It does

not sufficiently take into account the particular social identity of certain categories of persons such as adolescents who face a strong asymmetry in their relationship with adults. Furthermore, trust is often reduced to that which can be experienced by the person with a chronic situation towards professionals, and the construction of this relational climate in the dynamics of interactions is not sufficiently problematized. It is therefore necessary to consider that this situation is based on the construction of a relationship of mutual trust between adolescents with a chronic condition and the professionals who care for them as well as between these adolescents and family caregivers (Perdriger and Michinov, 2015). Social psychology research on the theme of trust invites us instead to conceptualize this relational climate by considering the social context that shapes the interactions in therapeutic education as well as the expectations and perceptions at stake in these interactions (Marková and Gillespie, 2008). Drawing on psychosocial approaches would allow us to understand the construction of trust through common-sense knowledge that individuals tap into in their socio-cultural context to give meaning to communications and interactions in daily life (Pirttilä-Backman et al., 2017).

### ***Construction of trust and social representations***

The social representations framework (Moscovici, 2008) offers a heuristic theoretical framework for understanding how the relationship of trust is constructed between adolescents and adults in the therapeutic situation. Social representations can be defined as a kind of knowledge that is socially developed and shared, having a practical aim and contributing to the construction of a reality that is common to a social group (Jodelet, 1989). The author associated with this definition proposes to distinguish three “spheres of belonging of representations” (Jodelet, 2012) whose articulation would allow us to better understand the construction of the trust relationship in the therapeutic situation: the intra-subjective, inter-subjective and trans-subjective spheres.

The *intra-subjective sphere* refers to the set of representations that individuals draw on to understand their subjective and social experience (Jodelet, 2013). In our case these interpretive frameworks

would allow the participants in the therapeutic situation to give meaning to the climate of their relations. However, social representations do not only have the function of giving meaning to lived experiences. Related to the *inter-subjective sphere*, this type of representation also produces expectation and anticipation systems that govern communication and interactions in the field of intimate exchanges (Jodelet, 1989; Maisonneuve, 1966). Access to the representations of the participants in the therapeutic situation would make it possible to study the relationships they are likely to develop, but also to understand how trust is constructed through these relationships. It should be considered here that these participants do not necessarily have the same freedom of action in social relationships that characterize the therapeutic situation. For instance, professionals and parents are socially recognized as having responsibility and decision-making powers over treatment choices, which can reduce the ability of adolescents to defend their own expectations in the negotiation of therapeutic goals.

An in-depth analysis of the relational climate between participants in therapeutic education therefore requires the situation to be contextualized within a broader social system that shapes the processes of subjective and inter-subjective order. This work can be carried out from the *trans-subjective sphere*, where social representations are considered as a set of beliefs, norms and values that have a function of social integration and of maintenance of social order. In matters of trust in particular, these representations help to strengthen affinities between the individuals who reciprocally adhere to it (Jovchelovitch, 2007). Specifically, trust is a “good” of belonging and affiliation that is characterized by the presumption or recognition of the other as an individual sharing the same system of norms and values that we adhere to ourselves (Maisonneuve, 1966). This perspective allows us to problematize the construction of trust between adolescents and adults, through the encounter between shared representations, based on which they build common expectations and aspirations faced with the challenges of self-management. It is also on the basis of these shared representations that individuals call on the other as a member of a specific age group, and that they are likely to recognize his or her skills in coping with the pathology and to trust him or her in return.

## ***Paediatric diabetology: A relevant context***

Type 1 diabetes in a paediatric context is a prototypical field for conceptualizing the relationship of trust through the articulation of the three spheres of belonging of social representations. This pathological field is both a pioneer in the development of therapeutic education and a vehicle for health and psychosocial issues shared by other types of chronic conditions during adolescence. Specifically, adolescents living with diabetes are in a critical transitional period that requires them to acquire autonomy and responsibilities in the management of pathology (Anderson and Wolpert, 2004; Cameron et al., 2014). However, this work is not easily achievable. Parents may have difficulty helping to empower their child when they have been accustomed to taking full responsibility for managing diabetes since his or her childhood (Rankin et al., 2011). The relational climate maintained with professionals is also crucial in the process of empowering adolescents with diabetes, since the latter are less likely to collaborate when they feel that they are judged and not supported by professionals (Wilson and Endres, 1986). In addition, adolescent distrust in adult care delays the transition from paediatric services to adult services (Morsa et al., 2017). Diabetes during adolescence is therefore a relevant context for exploring the issue of trust in therapeutic education.

## ***This study***

Following on from previous studies in the French context (see Colson et al., 2016a; Fonte et al., 2017a), this paper aimed to better understand the construction of the climate of trust that adolescents maintain with their parents and professionals in the context of therapeutic education. On the basis of the three spheres of belonging of social representations (Jodelet, 2012), our objectives consisted in:

- Identifying representations that allow each participant to feel the trust he or she can have in the other concerning the management of diabetes (intra-subjective sphere);
- Comparing representations of these participants in order to understand the construction of trust in the dynamics of social

- interactions (inter-subjective sphere);
- Deepening the trust between these participants as a symbolic resource shaped by systems of norms and values that govern their interactions (trans-subjective sphere).

## **Methods**

### ***Study design***

This qualitative study is part of broader inductive research aiming to explore the expectations of adolescents living with diabetes, their parents and the professionals who take care of them, in order to design therapeutic education programmes that better respond to their needs (ClinicalTrials.gov – NCT02859779). The inductive approach is characterized by the observation of a particular phenomenon in the field in order to construct a theory for describing it and understanding it (Glaser and Strauss, 1967). In our case, the relationship of trust was not integrated into our original research question. An open coding allowed the theme of trust to emerge from the analysis as an unexpected and salient incident in the data. A selective coding was then carried out in order to identify all the sub-themes associated with the theme of trust. The social representations approach allowed us to adopt a psychosocial reading of the data while maintaining the possibility of observing the particularities of the phenomenon studied (Dany, 2016).

### ***Recruitment and sampling***

The research was conducted in five French healthcare establishments which specialize in paediatric diabetology and set the following criteria for the participants: to be an adolescent living with diabetes or a parent of an adolescent with diabetes between 11 and 16 years of age and diagnosed for more than six months, or to be a professional in the paediatric diabetology department. In order to explain the objectives of the research and the associated ethical conditions to the potential participants, an information meeting was organized with adolescents, parents and professionals in each study environment. The



volunteers were asked to give their written consent to participation in the research. Parents also gave consent regarding adolescents who wished to participate in the research. Sampling of this study was based on voluntary participation and there was no limit to the number of participants.

### ***Data collection***

The focus groups (FGs) were facilitated by a social psychologist and a paediatric nurse (the two first authors) who were not attached to the health establishments in which the participants were being treated. This qualitative method promotes social interaction between participants and encourages them to build their discourses on the comments of the others (Krueger and Casey, 2009). FGs are considered as a communication space which makes it possible to explore socially shared knowledge (Marková et al., 2007). From the social representations' perspective, FGs allow the social dynamics at stake in the construction of representations to be observed and analysed (Caillaud and Kalampalikis, 2013). In our case, the social dynamic refers to disagreements, conflicts, or consensuses at stake in the construction of discourses about trust. The different types of participants (i.e., adolescents with diabetes, parents and professionals) were not mixed in the FGs in order to neutralize statutory asymmetries that could prevent everyone's freedom of expression. The FGs were conducted in a quiet area of one of the educational establishments and lasted between 40 and 60 minutes.

The interview guide (see Appendix 1) included questions which explored several themes, such as: the representations and experiences of diabetes, the difficulties caused by the chronic condition on a daily basis, its impact on family life, or even the expectations of change in order to improve therapeutic education sessions. In order to follow through and examine the answers in greater depth, each idea expressed by participants was subject to new questions (e.g., "Can you tell me a bit more about that? Do you have examples to illustrate that?") and discussions with the group (e.g., "What do you think of what he or she has just said? Why do you agree or disagree?"). Discourses produced by these questions were recorded and fully transcribed for analysis.

## ***Data analysis***

A thematic content analysis (Flick, 2014) was performed in order to explore the topics discussed by participants that reflected representations and lived experiences of the relational climate in the therapeutic situation. The analysis was performed via a systematic identification of emerging themes expressed in each discourse about the relational climate that adolescents experienced with professionals or their parents and vice versa. Emerging themes can be defined as phrases that reflect the psychological essence of a discourse extract (Smith et al., 2009). This work was carried out in several steps. The interviews were first printed and read in full in order to thoroughly absorb the data. Annotations were added in a handwritten way in the margins of the printed transcriptions to identify key ideas, images, expressions or metaphors used by participants to talk about the relational climate with the other. These descriptive notes were then transformed into emerging themes through a connexion with psychosocial concepts. Finally, we were attentive to the agreements and disagreements that each theme could arouse when they were discussed in the FGs.

We developed a continuous reflexivity throughout the data analysis process to ensure the credibility of our interpretations. The emerging themes of the analysis and the conceptual abstraction were carried out by a junior social psychologist (first author) whose work had been discussed with two other investigators. One of them was a paediatric nurse (second author) with professional experience in the care of children living with a chronic condition. The other was a senior social psychologist (last author) highly trained in the qualitative health research area. This methodological strategy allowed us to produce a meaningful analysis from both clinical *and* psychosocial standpoints.

## **Results**

A total of 46 participants were recruited (see Appendix 2). The sample of adolescents consisted of 26 participants (15 girls and 11 boys) divided into 6 FGs. The sample of parents consisted of 9 partic-

ipants (5 women and 4 men) divided into 2 FGs. For reasons of constraint and feasibility, we were unable to interview parents and adolescents who were systematically part of the same family. The sample of professionals consisted of 11 participants (10 women and 1 man) divided into 2 FGs. These were multidisciplinary groups including four paediatricians, four nurses, two dieticians, and one psychologist. The thematic content analysis showed that the relationship of trust was a central concern for a number of participants: on the one hand, it was a salient and spontaneously mentioned theme (i.e. was not induced by the questions of the researchers) in 4 out of 10 FGs in talking about the context of relationships between adolescents and professionals and between adolescents and parents; on the other hand, this theme referred to a relational experience related to the mobilization of self-management skills. The sub-themes and extracts from the qualitative analysis are presented in Appendix 3.

### ***A misunderstanding between adolescents and professionals***

Adolescents from FG5 discussed the issue of trust through their relationship with professionals. Some highlighted the lack of trust that these professionals may have in their regard, especially because they do not sufficiently recognize the constraints of self-management that can be experienced on a daily basis. Adolescents characterized this lack of recognition by the fact that professionals would see non-adherence primarily as an intentional act. Faced with this misunderstanding, adolescents then displayed their incomprehension by wondering why the professionals would suspect them of trying to voluntarily create episodes of hypoglycaemia or hyperglycaemia. In order to give meaning to the reactions of the professionals, the group agreed consensually to the idea that they “don’t adapt very much to our situation, they don’t try to say why we do that” (FG5, girl #1), that they “rely mainly on the patients they had” (FG5, girl #2) “before” (FG5, boy #1) as well as “on the disease, and not necessarily on us, on what we feel.” (FG5, girl #1). This consensus illustrates the socially shared meanings associated with the lived experience of the relationship with professionals. These meanings provide adolescents with useful answers for understanding and mastering these interactions.

The discourse of professionals from FG10 offered a better understanding of the relational climate that they were likely to maintain with adolescents. Belonging to the same health establishment in which adolescents from FG5 were treated, these professionals all agreed that constructing a relationship of trust with adolescents was a prerequisite for empowerment work in diabetes management. This mutually agreed stance is based on the fact that it enables “them to know us better and us to know them better” (FG10, paediatrician #2) in order to “create a link” (FG10, paediatrician #1) and “more facilitated dialogue” (FG10, paediatrician #2). Some professionals also thought that adolescents would sometimes seek to voluntarily break the relationship of trust by adopting non-adherence behaviours. Adolescents’ reactions were then interpreted by professionals as a need to test the strength of the links they could have with them and to see whether they could trust them.

### ***Adolescent facing self-management: Ambivalent parents***

The relationship of trust was also discussed by adolescents from FG5 as part of the relationship with parents. Part of the group complained about their parents’ lack of trust when they tried to “manage diabetes alone” (FG5, Boy #1). Specifically, certain adolescents had the feeling of being constantly monitored for insulin injections, of not being adequately listened to in decisions about treatment or being unfairly reprimanded for blood glucose levels that did not reach the objectives set by the professionals. These adolescents then referred to interaction situations with their parents which they said they did not understand: “Sometimes my blood sugar levels aren’t so good, and my parents actually blame me for it” (FG5, girl #1); “My brothers eat cakes, there are cake wrappers lying around. But me, I’m in the lounge, I’m hyperglycaemic, and they say to me: well, you’ve eaten cake, it’s your fault” (FG5, boy #2). Furthermore, some adolescents shared the feeling that parents were not letting them sufficiently apply the advice given to them by professionals to manage diabetes more effectively. To explain this reaction of distrust, an adolescent thought that medical information lost all credibility for parents if it was communicated through adolescents and not directly by professionals: “It

has to be the professional person who says it. No-one could care less about what I say, it's like I was going to lie to them" (FG5, girl #1).

Parent groups, for their part, constructed discourses that oscillated between feelings of trust and distrust of adolescents. For instance, parents from FG7 spoke of their child as being "very reasonable" (FG7, mother #2) and able to "fend for themselves" (FG7, mother #1) in diabetes management while highlighting the need to pay attention to them and monitor them. For many parents, the theme of distrust was accompanied by negative emotions which characterized the relationship with their child. Expressions such as "I'm scared", "It's very hard" or "It's stressful" marked the discourse of parents when talking about their child's behaviour faced with diabetes, and their fear of letting them handle treatments alone: "What stresses me is when he's not in the house... I'm frightened that he has forgotten to check his blood sugar, that he won't come back, that he's not doing what he should do" (FG7, mother #2). This distrust was justified by the idea that their child was above all an adolescent like others, sharing a reckless, puerile and immature attitude to the advice of the professionals: "He's a teenager, he has the right to be carefree" (FG7, father, #1); "For seven or eight months he's been messing around saying 'Oh, blast, I've forgotten to do my injection' before meal times" (FG7, mother #2). This social knowledge, which draws on the archetype of the adolescent and helps to legitimize the feeling of distrust, was the subject of a greater discursive focus in FG8. Parents emphasized the difficulty of getting their child to adhere to dietary recommendations because: "Teenagers don't listen, and they eat everything" (FG8, mother #2). Several parents then spoke of the attitude of systematic contradiction and opposition of adolescents who wanted to eat sweets only because they are forbidden: "Since his diabetes was diagnosed, you'd say he was doing it deliberately, he's stopped following the rules, he doesn't ask anymore he just helps himself to sweets" (FG8, mother #3).

## **Discussion**

Our objective was to explore the representations that give meaning to the relational climate between adolescents with diabetes and parents as well as between these adolescents and professionals. A

thematic content analysis allowed us to analyze the intra-subjective sphere of the representations. Adults expressed an ambivalence in the feelings they may have in their relationship with adolescents: on the one hand, the need to trust adolescents to help empower them in diabetes management; on the other hand, a feeling of distrust inspired by the idea of carelessness and irresponsibility that is thought to characterize adolescence. Adolescents, for their part, seemed relatively clear-sighted about how they could be perceived by professionals and their parents. They had the feeling that adults were suspicious of them because they would try to lie about the follow-up to treatments and not voluntarily listen to the advice of professionals. Adolescents then criticized adults for not trusting them enough and for not trying to understand the day-to-day constraints of self-management.

With regard to the inter-subjective sphere of representations, these communication data seem to indicate that the relational climate in a therapeutic situation is marked by many tensions and misunderstandings between the expectations that each kind of participant in a therapeutic situation can have of the other. Some adults would seek to anticipate and master interaction situations with adolescents by drawing on the common-sense knowledge that characterizes adolescence as a period of life naturally focused on risk-taking (e.g., being reckless and sacrificing one's future health to immediate pleasures). The identity assignment of adolescents with diabetes as members of a category socially defined by recklessness in the face of health issues is then likely to play a determining role in the reification of the socio-affective relations that adults have with this population. This context could lead adults to a denial of the unintentional nature of certain behaviours that may be induced by constraining social situations. Indeed, the data analysis pointed out that many adolescents felt that both parents and health professionals did not believe them when they tried to talk about the difficulties they experienced in diabetes self-management. On the other hand, adults interpreted these difficulties as intentional attempts to test the rules imposed on them in order to follow medical recommendations. Thus, we observed the existence of a complex and dynamic circularity in the construction of the relational climate, where the mistrust of some is always likely to reinforce that of others. These results are consistent

with those of Whittemore et al. (2017), in which parents of adolescents living with Type 1 diabetes report the difficulty of maintaining a balance between their child's desire for independence and parental control to avoid triggering relational conflict. Our results are also close to those of Chao et al. (2015), in which family life is seen as an important stressor (e.g., parental harassment, family conflicts) that hinders adolescents' desire for autonomy and reduces their feeling of self-efficacy in diabetes self-management.

Common-sense knowledge about adolescence should also be considered as representations which are both culturally and historically situated. The interpretive framework that gives meaning to the relational climate between each participant in the therapeutic situation must then be contextualized in the trans-subjective sphere of representations in which identities and social existence are shaped (Jodelet, 2012). Specifically, the way in which parents and professionals think about and experience their relationship with adolescents with Type 1 diabetes in France probably finds its socio-genesis in the biopolitics of the 19<sup>th</sup> century, when medical-psychological knowledge constructed the representation of a youth dangerous to its own health in order to legitimize control and surveillance of this social category (Foucault, 1979). The representation of a youth at risk remains highly prevalent in the fields of health and prevention policies in the French context, despite the sociological criticisms that have been produced due to the current state of scientific knowledge and the lack of comparative studies on health behaviours of different age categories (Loriol, 2004).

However, it is important to consider that the representation of at-risk youth is not specific to the French context. Institutional discourses from Western societies historically marked by liberal individualism could also help to maintain stereotypes about young people under the guise of scientific legitimacy. For instance, adolescents in the Canadian press are mainly presented as being dangerous to themselves or dangerous to others (Claes, 1992). These representations have also been widely circulated through the globalisation of communication (Steinberg and Lerner, 2004). In a number of non-Western societies, there is competition between traditional positive representations of adolescence and negative representations communicated by the media, as has been observed in

India (Thapa et al., 1999), Africa (Dasen, 2000) and Brazil (Pereira and Heringer, 1994). These representations of adolescence are important to consider in therapeutic education because they can influence the resources and options that adults make available to adolescents living with a chronic condition.

These socio-cultural considerations raise the question of the normative and ideological anchoring of the representations of adolescence. Specifically, the archetype of the reckless adolescent would only make sense in a relation of opposition to the archetype of the autonomous and responsible adult as can be promoted in the ideological context of Western liberal societies (Arnett, 2006). This opposition is interesting to point out, since it has been shown that the adoption of diabetes self-management behaviours is associated with the acquisition of an adult identity in the neoliberal context (Fonte et al., 2018a). Thus, in the context of therapeutic education, professionals and parents are always likely to maintain a climate of distrust towards adolescents with diabetes because they would presume an adherence on their part to values that are at odds with those of the adult world. Constructing a relationship of trust with adolescents would therefore not be self-evident for adults, since they would not recognize an adult identity constituted by the neoliberal value of autonomy.

### ***Practical implications***

The findings of our study have several practical implications for improving the relationship of trust between each participant involved in therapeutic education. Professional training should incorporate this type of knowledge in order to better understand the psychosocial processes and issues of the therapeutic situation. One solution could therefore be to implement a practice analysis aimed at providing professionals with a space for reflection on their relational posture with adolescents and the socio-cultural stereotypes they bring into play in these interactions (Fonte et al., 2018b, 2017b). To the extent that intra-family relationships are determinants of empowerment in the management of Type 1 diabetes (Naranjo et al., 2014; Neylon et al., 2013), maintaining a relationship of trust between parents and adolescents with diabetes is essential. For instance, family conflict is



regularly associated with suboptimal blood glucose levels in the literature (Neylon et al., 2013). Therefore, some parents should learn to change the nature of their relationship with their child from a paternalistic to a cooperative attitude that encourages more shared care responsibilities (Cameron et al., 2014). A discussion group or peer coaching intervention (Tully et al., 2017) could then be carried out with parents in order to strengthen the relationship of trust within families and thus better respond to the expectations of adolescents who request increased empowerment.

A greater involvement of adolescents with diabetes in the various steps of the conception and implementation of therapeutic education programmes is also an important issue for promoting therapeutic alliance. This approach would make it possible to move away from paternalistic approaches by professionals who develop therapeutic education programmes for adolescents without even consulting them, defining in their place what would be best for them in terms of medical recommendations (Colson et al., 2016b; Fonte et al., 2014). For instance, annual assessments should be carried out through group meetings between adolescents rather than individually with professionals to review the past year and discuss the problems encountered during this period among peers. The educational team could also organize theme evenings for adolescents and young adults who both have diabetes to discuss the difficulties experienced in managing the chronic condition during puberty. By recognizing the experiences of adolescents with diabetes as real skills that adults need to be able to rely on, this participatory approach should reinforce their capacity for empowerment as well as the climate of trust they can experience in the therapeutic or family relationship.

### ***Limitations and future research directions***

The present study has two main limitations. The first refers to the absence of any specific questions about the relationship of trust in the interview guide, which limits our understanding of the meanings that participants are likely to associate with the climate of their relationship with others. However, our work could provide valuable information for future research that would explore the relationship of

trust between adults and adolescents living with a chronic condition in a more systematic and in-depth way. The second limitation concerns the specificity of the population studied. However, our results are transferable to comparable therapeutic situations in different chronological and populational contexts. Many chronic conditions that need to be managed in adolescence share the same relational issues as Type 1 diabetes. They involve a therapeutic need to establish a relationship of trust with adolescents in a context where representations of adolescence are always likely to elicit distrust.

Future socio-representational studies should examine further the construction of trust with the different kinds of populations encountered by professionals providing therapeutic education. The theoretical framework of social representations allows us to conceptualize trust in therapeutic education through articulating the different levels of analysis in order to contextualize representations with the socio-cultural inscription where they are shaped. One of our main findings which should be studied more systematically is the decision to distrust or not distrust others according to how their identities are constructed in the ideological context of reference. This could involve examining the interplay of positive and negative representations of adolescence, how this interplay influences the empowerment of adolescents living with a chronic condition, and the conditions under which professionals and family caregivers would be most receptive to these different representations. Such work could provide an original contribution to the understanding of psychosocial determinants of self-management behaviours in therapeutic education.

### **Ethical considerations**

Authorization for the research was given by the National Agency for the Safety of Medicines and Health Products (ANSM-France). Ethical approval for this research was obtained from the Committee for the Protection of Persons (CPP-France). The processing of computer data was authorized by the Commission for Data Protection and Liberties (CNIL-France).

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# Appendix 1

## Interview guides for the focus groups

Focus groups of adolescents and parents	Focus groups of professionals
When I say the word “diabetes”, what are the first words that come to mind?	When I say the word “diabetes”, what are the first words that come to mind?
What is the most difficult thing about diabetes to live with?	What is the most difficult thing about diabetes for adolescents to live with?
What would you like to change?	What difficulties do you encounter in the management of diabetic adolescents?
Who makes decisions about diabetes treatment most often?	What are the driving forces in the management of this population?
What happens in your family if there are difficulties with diabetes?	What are the difficulties you encounter in implementing educational sessions?
How would you like this to happen in your family for you to live better with diabetes?	What would you like to change to improve the educational sessions?
What would you like to change to improve your management and educational sessions?	

# Appendix 2

## Composition of the ten focus groups (FGs)

FG	Adolescents (n = 26)	Parents (n = 9)	Professionals (n = 11)
1	3 girls		
2	2 girls 3 boys		
3	5 boys		
4	2 girls 1 boys		
5	3 girls 2 boys		
6	5 girls		
7		2 mothers 2 fathers	
8		3 mothers 2 fathers	
9			2 pediatricians 2 nurses
10			2 pediatricians 2 nurses 2 dieticians 1 psychologist



## Appendix 3

### Sub-themes and extracts characterizing the relationship between participants

	Sub-themes	Typical extracts
Adolescents about professionals	Professionals... <ul style="list-style-type: none"> <li>• Don't trust me enough</li> <li>• think that I am intentionally not adherent</li> <li>• focus on my illness and not on my own life experience</li> <li>• don't have an understanding attitude towards me</li> </ul>	<p>"I'd like them to trust us more! But, all the same, there are some people who trust us here. But of course, that depends on the people. Personally, I've no problem about trust with the nurses. But, for example, it's true I'm a bit slow in doing my injections, but it's just that sometimes it really hurts." (FG5, girl #1)</p> <p>"There are some doctors who think that I inject myself or don't inject myself to make myself either hypoglycemic or hyperglycemic. Never mind the fact that it'll soon be thirteen years that I've had diabetes, and I know what it means, (...) I'm not going to put myself in danger, especially when I don't like being in hospital, and I'd prefer to be outside." (FG5, girl #2)</p>
	Trust is a therapeutic tool for autonomy	"I was going to say the therapeutic relationship, but that's it. Because I think that in the beginning, nothing will happen if they don't trust us. But once you really get past that it's much easier to make progress with them. (FG10, pediatrician #1) "
Professionals about adolescents	Patient non-adherence... <ul style="list-style-type: none"> <li>• is associated with a breach of trust</li> <li>• is often intentional</li> </ul>	There are some who establish a bond easily, but they often try to break it, and when they break it they are non-compliant. They try to re-establish the same bond they might have at home, to repair it and to check that it's strong" (FG10, psychologist #1)
	My parents... <ul style="list-style-type: none"> <li>• don't trust me</li> <li>• are constantly watching me</li> <li>• don't believe me</li> <li>• prevent me from applying the advice of the professionals</li> </ul>	<p>"They don't trust us. They don't tell themselves that we have to do everything alone, manage diabetes all on our own. They are always behind us, always checking up on us." (FG5, boy #1)</p> <p>"My parents think they know everything. When a professional tells us, in fact, you have the right to a little bit of everything, but just a certain amount, in fact, it's no good me telling them that, they won't listen. It has to be the professional who tells them. They couldn't care less what I say, it's as if I was lying to them. It's 'no, you're not right you mustn't do that' Or for example, when I'm eating 'be careful' all the time. So, well I don't know, it's annoying" (FG5, girl #1)</p>
Adolescents about parents	My child is capable of being reasonable and autonomous	"From the early days he has done his injections, I was very impressed! But even so we're there to keep an eye on things, because he's a teenager, and he has the right to be carefree." (FG7, father #1)
	But adolescents... <ul style="list-style-type: none"> <li>• are reckless and immature</li> <li>• don't like to follow the rules</li> </ul>	"The rules already existed before, yet he challenges all the rules. He says that there are more rules since he's been diabetic, when in fact the rules were the same before. Now, he opposes any type of rule that exists, he totally opposes all that. (FG8, mother #2)
Parents about adolescents		