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Representations and experiences of well-being among diabetic adolescents: Relational, normative, and identity tensions in diabetes self-management

David Fonte[1], Sébastien Colson[1,2,3,4], José Côté[4,5], Rachel Reynaud[6], Marie-Claude Lagouanelle-Simeoni[1,7] and Thémis Apostolidis[1]

Abstract

We explore representations of well-being in adolescents with Type 1 diabetes in order to better understand their expectations and needs in therapeutic patient education. In total, 28 interviews were performed and then submitted to thematic content analysis and lexicometric analysis. Results show the intervention of psychosocial processes in the relationship that adolescents maintain with well-being and self-management. More specifically, we observed that well-being is impacted by areas of tension between the expectations of adolescents and the therapeutic objectives expressed by health professionals. These tensions should be taken into account in the conception, implementation, and evaluation of therapeutic education programs.

Keywords

adolescents, patient education, qualitative research, Type 1 diabetes, well-being

Introduction

Therapeutic patient education was established as an essential practice for supporting patients suffering from a chronic disease. This interventional field aims to help patients acquire the skills they need to manage their lives with a chronic disease as well as possible, so they can take responsibility for their own care as a means of maintaining or improving their health (World Health Organization (WHO), 1998), that is, a state of physical, mental, and social well-being (WHO, 1948). This issue is an even more sensitive one among adolescents, where the management of a chronic disease occurs during a time characterized by complex changes that may

[1] Aix Marseille Univ, LPS, Aix-en-Provence, France
[2] APHM, Coordination générale des soins, 13005, Marseille, France
[3] Aix Marseille Univ, SPMC, Marseille, France
[4] Université de Montréal, Faculté des Sciences Infirmières, Montréal, Canada
[5] Centre de recherché du centre hospitalier de l'Université de Montréal, Montréal, Canada
[6] APHM, Hôpital de la Timone Enfants, Service de pédiatrie multidisciplinaire, Marseille, France
[7] APHM, Hôpital Conception, Service d'évaluation médicale, 13385, Marseille, France

Corresponding author:
David Fonte, Laboratoire de Psychologie Sociale, Aix-Marseille Université, 29 avenue Robert Schuman, 13621 Aix-en-Provence, France.
Email: david.fonte@univ-amu.fr

have many consequences for well-being (Michaud et al., 2007).

According to a systematic review by Barlow and Ellard (2006), the literature in the field of chronic illness usually assesses adolescent well-being through general psychosocial constructs such as scales measuring quality of life or anxio-depressive disorders. They highlight the lack of interest in the personal meanings that adolescents associate with well-being, making it more difficult to identify and develop skills that respond to their needs. In addition, we believe that another limitation of the literature analyzed by these authors may be the partial character of the problematization of the "social," in the sense that well-being is rarely studied beyond its connections with a social context reduced to simple interpersonal relationships. Today, well-being of adolescents engaged in therapeutic patient education is still conceptualized within a relatively individualistic perspective that does not consider the construction of reality *in* and *through* social life.

However, difficulties in the study of well-being are not restricted to the fields of therapeutic education or chronic disease. Well-being is a catch-all concept that gives rise to vague and overly broad definitions in the literature (Forgeard et al., 2011). To fill this gap, a new conception of well-being was proposed by Dodge et al. (2012). These authors think that the well-being of adolescents is the result of a balance between the challenges of life they face and their ability to adapt to the available resources to meet these challenges. According to this definition, the balance between resources and challenges depends on the dynamics of the social context and the sense of mastery that adolescents have, depending on their perception of the situation. It is therefore important to better understand the way in which these adolescents represent well-being and the sense of control they feel they have over it, as well as conditions that affect this well-being in daily life.

The social representations approach (Moscovici, 1984, 2001, 2008) offers a heuristic theoretical framework for understanding representations of well-being from this perspective. 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). In everyday life, these systems of representations provide individuals with an interpretive framework to give meaning to their social experience and their subjective experience with a chronic disease (Jodelet, 2006, 2013). Applied to our target population, this socio-constructivist approach aims to reconsider the lived experience of adolescents as part of a world of objects that they will represent through interaction with peers and adults (Corsaro, 1990; Garnier et al., 1996). Therefore, this perspective allows us to problematize representations of well-being in adolescents with chronic disease by taking account of their lives within processes of social inscription and participation. On one hand, by their membership to both groups of adolescents and of young people with same disease, they have representations and social experiences specific to these aspects of their identity. On the other hand, these membership groups maintain social and symbolic relationships with others groups, such as the relations of power and obedience related to normative expectations of parents and caregivers. The perspective of social representations invites us here to study well-being as an object which is affected by values, norms, and aspirations specific to each protagonist in the situation (Kalampalikis and Apostolidis, 2016). This convergence of viewpoints may allow us to better understand the social construction of meanings that make sense of representations of well-being, by taking into account the particular social contexts within which adolescents with chronic disease operate.

Type 1 diabetes is a prototypical field for conceptualizing subjective well-being in this dynamic and relational perspective. This pathological field is both a pioneer in the development of therapeutic patient education and a vehicle for health and psychosocial issues shared by other types of chronic illness. Diabetic adolescents socialize in areas which contribute to the construction of their social identity, including through the close relationship they maintain with protagonists in the health system. These adolescents learn to acquire self-management skills that must be mobilized everyday and be updated regularly in order to prevent diabetes-related complications and to improve well-being (Cameron et al., 2014). To do this, they must achieve glycemic objectives set by health professionals, by learning to manage insulin injection, diet, and physical activity (Lange et al., 2014; Swift, 2009). However, the acquisition of autonomy and responsibilities in diabetes management is not easy for everyone and is hard to cope with during the period of adolescence. It is common to observe the adoption of a passive and non-compliant attitude toward the constraints of diabetes (Cameron et al., 2014), which assumes the emergence of tensions between the expectations of adolescents and the therapeutic objectives of health professionals. The context of therapeutic patient education in pediatric diabetology is therefore a particularly suitable field for the study of psychosocial processes from which the meanings associated with well-being arise.

The aim of our research is to study the representations of well-being in diabetic adolescents, in order to better understand the needs of this type of patient engaged in therapeutic patient education. Specifically, the objectives consisted in:

- Identifying representations (beliefs, knowledge, field of values, experience) that give meaning to well-being;
- Exploring how this system of representations constitutes a modality of thinking that is socially situated and constructed;
- Grasping the role of self-management skills and the place of others in these representations;
- Better understanding psychosocial issues underlying the representations of well-being and self-management in order to establish operational recommendations for action in therapeutic patient education.

Methods

Participants and procedure

This qualitative study is a part of a broader research project aiming to evaluate the development of socio-cognitive and clinical profiles in a cohort of diabetic adolescents participating in a therapeutic education program (see Colson et al., 2016a). This research was conducted in two French health establishments which specialize in pediatric diabetology and set the following criteria for the participants to be between 12 and 17 years of age, diagnosed with Type 1 diabetes for more than 6 months, and fluent in spoken and written French. An information meeting was organized in order to explain to adolescents and their parents the objectives of the research, the conditions, and mode of participation, as well as the ethical conditions governing this work (recruitment based on voluntary participation, confidentiality of data, and possibility of leaving the study without consequences for usual care). Sampling of this study was based on the voluntary participation of patients who had enrolled in a therapeutic education program. Out of a total of 34 patients who participated in this program, 28 agreed to take part in this study. This sample size provides sufficient variability and heterogeneity concerning patient profiles. Ethical approval for this research was obtained from the ethics committee of Montréal University (Quebec) and the Committee for the Protection of Persons, Southern-Mediterranean II (France). A physician from the study environment carried out the enrollment visit. Volunteer adolescents and at least one of their parents or legal representatives were asked to give their written consent to participation in the therapeutic education program and the associated research.

Data collection

A social psychologist performed 28 semi-structured individual interviews at the time of enrollment in the cohort, as part of the qualitative assessment. This professional was not part of the educational team and did not participate in the facilitation of therapeutic education sessions. He was put in contact with the patients by a pediatric nurse from the team. These interviews were conducted in a quiet area of one of the educational establishments and without the presence of parents. The interviews lasted between 20 and 40 minutes, depending on the participants and the temporal constraints of the parents or health professionals. These constraints mainly concerned certain aspects of care that were considered as priorities for patients: enrollment visit with an investigating physician from the study environment, explanation of the therapeutic education program and the associated research, signing of participation consent, performance of an educational diagnosis with a pediatric nurse from the study environment, and participation in the quantitative assessment of the program. The questions asked in the interview were therefore treated in less depth with some patients in order not to disturb the work of health professionals or to adapt to the busy schedule of some parents. These interviews were recorded and fully transcribed for analysis.

A structured interview guide was designed according to Smith's (1995) recommendations. The guide was identical for each participant in order to ensure comparability of results and to allow them to express the perceptions, images, attitudes, and experiences they associate with well-being. It was identical for each participant in order to ensure comparability of results and to allow them to express the perceptions, images, attitudes, and experiences they associated with well-being. This guide contained the following questions allowing well-being to be approached from a general viewpoint and then in the reality of the lived experience: "When I say *well-being*, what are the first words or images that immediately come to your mind? What do they mean to you?" and "In which situations do you feel better in your life? And in which situations do you feel worst?" Each idea expressed by participants was subject to new questions allowing us to persist and examine the answers in greater depth (e.g. "Can you tell me a bit more about that? Do you have examples to illustrate that?"). In order to explore the conditions of spontaneous emergence of the self-management issue when participants expressed their point of view on well-being, themes related to diabetes and treatments were not induced by the social psychologist. The guide used for the qualitative evaluation also included other questions that have not been taken into account because they do not respond directly to our objectives.

To identify the profile of participants, clinical and socio-demographic characteristics were indicated after each interview. Glycated hemoglobin rate was collected in order to evaluate the quality of blood glucose control during the three months before the blood test. This rate is considered to be very risky for health if it is above 9 percent (Rewers et al., 2014). Also collected were the ages and gender of participants, the length of time that diabetes had been diagnosed, the mode of insulin therapy (multi-injection or insulin pump), and the marital status of parents.

Analytical procedure

Two thematic content analyses (Flick, 2014) were performed in order to explore common and shared themes by participants that reflected representations and lived experiences of well-being. The themes are the topics discussed by participants in their speech. The first analysis was performed via a systematic identification of frequent or salient themes addressed in each discourse on well-being, except in relation to specific themes related to diabetes, its treatments, and self-management. This work was carried out in several steps. A first thematic analysis grid was constructed on the basis of three main predefined themes: physical well-being, psychological well-being, and social well-being. Then, the interviews were read in full in order to categorize the subjects discussed by the participants in this grid. A new analysis grid was then created based on the pooling of all the subthemes addressed in each main theme. Finally, the interviews were completely re-read in order to recategorize the subjects discussed in this new grid. The second thematic content analysis was performed to examine further the specific place and role of diabetes self-management in representations of well-being. The analysis is based on a work of identification of frequent or salient themes related to self-management in the corpus, as well as the nature of the relationship these themes have with well-being. This work was carried out following the same analysis logic as in the first content analysis, with the exception of the two main predefined themes which this time were self-management as facilitating well-being and self-management as an obstacle to well-being. Presented interviews extracts were translated into English by a professional translator. They underline significant themes and reproduce discourses that underpin our analysis.

A lexicometric analysis was also performed with IRaMuTeQ[1] software in order to explore differentiated discourses on well-being, that is, oppositions between studied themes and their association with characteristics of participants (for examples of using this software as a tool to study social representations, see Danermark et al. (2013) and Guarnaccia et al. (2015)). Following the Reinert (1983, 1986) method, a top-down hierarchical classification was conducted with the aim of highlighting the formal structure of discourses. More specifically, it extracts significant similarities and oppositions between words via a χ^2 test of association and brings to light the lexical classes that represent different discursive focalizations within which words make sense. This statistical approach also offers us the possibility of visualizing meaningful connections between these classes and variable modalities. In our case, we used it in order to explore associations between discursive focalizations on well-being and some variables related to participant profiles (i.e. glycated hemoglobin rate and gender). Data analysis was characterized by a back and forth between successive steps performed within the interpretative framework of social representations (see Kalampalikis, 2003): identification of variables and words associated with each class, semantic contextualization from the extracts from where these words were derived, grouping the words into specific sub-themes and attribution of a general theme for each class from their respective sub-themes, and giving meaning to the relationship between each class from the top-down hierarchical classification. The Appendix 1 gives an example and a visualization of this process through a part of our results.

Results

The 28 patients who participated in the study were between 12 and 17 years of age (M = 13.8, standard deviation (SD) = 1.5), patients were mostly girls (64.3%), and their parents were mostly part of a couple (42.9%) or separated (39.2%). These participants had had diabetes from between the ages of 1 and 15 years (M = 6.9, SD = 4.2), their mode of insulin therapy was multi-injection (75.0%) or insulin pump (25.0%), and half of them (50.0%) had a glycated hemoglobin rate above 9 percent. Themes and sub-themes extracted from the three steps of the analysis are reported in Table 1.

A physical, psychological, and social conception of well-being

The thematic content analysis showed that some participants offered little description of their representations and experiences of well-being. Expressions such as “I don’t know,” “I know nothing,” or “nothing at all” marked the discourses of 71 percent of participants (with a total of 47 occurrences) and illustrated the difficulty of expressing an opinion on the question of well-being. The interview questions were then reformulated as many times as necessary, which allowed these participants to put what they thought and felt into words.

Despite this difficulty, the diversity of the discourses on well-being reflected representations shared by participants and helped to construct a common reality experienced by all kinds of adolescents. Well-being was viewed here in a pluralistic way, drawing on its physical, psychological, and social dimensions. According to participants, it was primarily

Table 1. Themes and sub-themes extracted from each analysis.

First step: thematic content analysis

Physical well-being
- Good physical health
- Absence of disease
- Balanced diet
- Physical activity

Psychological well-being
- Happiness and cheerfulness
- Self-acceptance
- Self-confidence
- Artistic activities

Social well-being
- Positive relationships with family
- Friendly environment
- Holidays and summer camps
- Academic activities

Second step: lexicometric analysis

Health and diet
- Good physical health
- Absence of disease
- Happiness and cheerfulness
- Self-acceptance
- Balanced diet

Diabetes and its management
- Performing insulin injections
- Avoiding gluttony
- Activities helping people forget about diabetes

Communication difficulties
- Talking with someone in one's close family
- Expressing one's own feelings
- Not being listened to
- Hiding diabetes at school

Worries and concerns
- Repetitive injunctions issued by adults
- Difficulties in changing lifestyle habits
- Hospital and medical appointments
- Recommendations by diabetologist
- Informing others that you are diabetic

Recreation and social activities
- Activities carried out with family
- Practicing sport with friends

Third step: thematic content analysis

Self-management as facilitating well-being
- Avoiding hypo and hyperglycemia
- Glycemic control
- Feeling well physically and mentally
- Playing outdoors and having fun

Self-management as an obstacle to well-being
- Repetitive and distressing self-care behaviors
- Sense of weariness
- Shame in front of non-diabetics
- Constraining and frustrating diet
- Repetitive injunctions issued by adults
- Weight of responsibilities

characterized by good physical health as well as an absence of disease that could lead to inactivity (43% of participants): "To be well you have to be in good health. For example, if you have the flu, you cough, you don't feel great. You want to stay in bed, because you're coughing" (P11, 14-year-old girl). This physical dimension of well-being, which dominated the discourse of participants, was promoted by individual behavior. Thus, having a balanced diet (21%) and engaging in physical activity (43%) were often seen as the necessary means of maintaining health and preventing disease: "You have to eat well so you don't get any problems" (P5, 16-year-old girl); "Sport's a must for me, it's good for your health" (P20, 16-year-old girl).

Well-being was also characterized by a positive psychological state. It was about being happy and cheerful (25%), but also of feeling good about ourselves, accepting ourselves as we are, and having self-confidence (29%). These states would be promoted by positive relationships with family or by a friendly environment (39%): "When I'm with my close friends or having a laugh, and all that, I feel great" (P22, 13-year-old girl); "When I'm with my parents, with my friends, well when I'm chatting you know, when I'm feeling good" (P6, 13-year-old boy). These relationships were sometimes mentioned in specific contexts such as school, holidays, beach, summer camps, or trips (14%): "I'm desperate to go to the beach this summer, to summer camp or the islands" (P11, 14-year-old girl). Some participants finally focused on solitary activities that allowed them to find peace and quiet, such as listening to music, drawing, or writing (7%): "Being alone with no one around, nothing around me, just me alone with some music" (P4, 13-year-old girl).

A diverse lexical network for thinking about well-being

The lexicometric analysis was performed in order to examine these results in greater depth. Having dealt with 70 percent of statements of the corpus, this analysis identified five lexical classes that reflected differentiated representations of well-being.

Class 1 concerned health and diet (24% of the analyzed corpus). Significantly associated lexical terms (all p's $< .05$) referred not only to a description of what "good" ($\chi^2 = 30.38$) "health" ($\chi^2 = 49.52$) was but also to the means of maintaining this state. More specifically, it is a state characterized by a lack of "disease" ($\chi^2 = 13.35$) and psychological "well-being" ($\chi^2 = 20.36$), that is to say, being "happy" ($\chi^2 = 13.35$) and being truly comfortable in one's own "skin" ($\chi^2 = 26.51$)[2] or "body" ($\chi^2 = 20.36$). It can be helped by a responsible "diet" ($\chi^2 = 13.35$) in the sense that it "takes" ($\chi^2 = 9.17$) "care" ($\chi^2 = 13.35$) of oneself and one's health. It is therefore a question of "eating" ($\chi^2 = 4.08$) "balanced" ($\chi^2 = 9.17$) meals, and especially of being careful about the consumption of sweet things and eating lots of vegetables. This class was associated with participants who had a glycated hemoglobin rate above 9 percent ($\chi^2(1) = 4.57$, $p < .05$).

Class 2 returned to the experience of diabetes (24% of the analyzed corpus). Significantly associated lexical terms (all p's $< .05$) referred to the "relationship" ($\chi^2 = 9.17$) maintained with "diabetes" ($\chi^2 = 12.94$) and its associated treatments. The words "moments" ($\chi^2 = 20.36$), "feel" ($\chi^2 = 29.28$), and "going" ($\chi^2 = 12.69$) related the emotions felt through this relationship. Thus, the most unpleasant moments are those when you have to carry insulin injections or avoid "eating" ($\chi^2 = 4.08$) foods we would like in order to avoid a too "high" ($\chi^2 = 9.93$) blood sugar count. Conversely, the pleasant moments are those that allow you to forget about diabetes for the moment, such as playing sports and activities with family or friends. This class was not associated with any variable.

Class 3 was about communication difficulties (16% of the analyzed corpus). Significantly associated lexical terms (all p's $< .05$) referred mainly to the difficulties of "talking" ($\chi^2 = 36.77$) with someone of his close family. It is thus a question of relationship issues with the "father" ($\chi^2 = 33.69$) when it comes to expressing one's own feelings. The latter can then give the feeling of not being sufficiently attentive to what may be communicated, such as anecdotes that happened in the day with "friends" ($\chi^2 = 5.57$) and problems related to diabetes. Mothers and some health professionals were conversely cited as being more attentive interlocutors who were easier to talk to ($\chi^2 = 6.00$). Finally, regarding relationships with classmates, diabetes was sometimes hidden due to "embarrassment" ($\chi^2 = 6.00$) and fear of being "seen" ($\chi^2 = 22.10$) differently. This class was not associated with any variable.

Class 4 related to worries and concerns (20% of the analyzed corpus). Significantly associated lexical terms (all p's $< .05$) referred to "things" ($\chi^2 = 36.61$), which are "continually" ($\chi^2 = 36.61$) repeated by relatives because they require particular attention. An example of this is the father who gets irritated easily

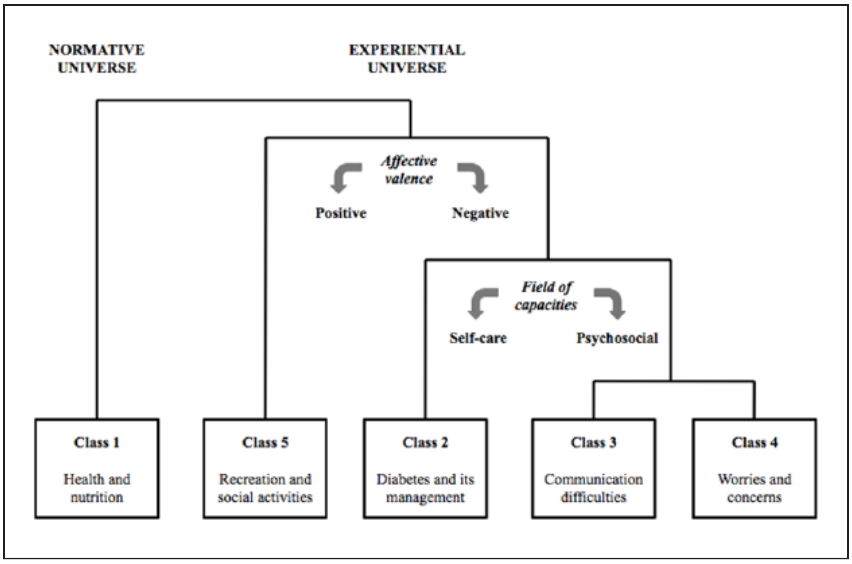

Figure 1. Links between lexical classes which structure discourse on well-being.

when something goes wrong, or even the doctor who continually issues the same warnings about the health risks of ineffective self-management. These repeated warnings could then result in adolescents “trying” ($\chi^2=4.29$) to change certain lifestyle habits despite the difficulties experienced, but could also create a lack of “desire” ($\chi^2=4.96$) to go to the diabetologist or follow their recommendations. People’s perception ($\chi^2=16.14$) of the disease was also a concern. Being “diabetic” ($\chi^2=4.29$) is a status that cannot be “seen” ($\chi^2=9.30$) at first, and which can therefore be hidden unless you inform others. This class was associated with participants who had a glycated hemoglobin rate of less than 9 percent ($\chi^2(1)=4.43$, $p<.05$).

Finally, class 5 was about recreation and social activities (17% of the analyzed corpus). Significantly associated lexical terms (all p’s$<.05$) referred to activities carried out with relatives and which are considered pleasing because they are “fun” ($\chi^2=4.70$). “Friends” ($\chi^2=46.65$) featured prominently in the discourse. They were mentioned in the context of “school” ($\chi^2=9.59$) or the practice of a group “sport” ($\chi^2=10.23$) such as “football” ($\chi^2=19.71$). Being with “family” ($\chi^2=24.84$) was also mentioned as a pleasant time and referred to memories of outings to the park or beach. This class was associated with participants who had a glycated hemoglobin rate above 9 percent ($\chi^2(1)=5.09$, $p<.05$).

A discourse on well-being structured by normative issues

The top-down hierarchical classification highlighted the structure of this network of meanings by tracing the fragmentation of classes from the corpus tree (Figure 1). The analysis of this tree showed a discursive opposition between two referential thematic universes: one that we call normative and the other experiential. In the normative universe, participants construct their representations of well-being through the use of common sense that taps into lay and medical knowledge. This knowledge refers to social norms that focus attention on personal health through a set of prescriptions and proscriptions about food. In our case, the participants furthest from the glycemic objectives set by health professionals (i.e. glycated hemoglobin rate$>$9%) were more focused on this normative discourse. They testified to a strong concern to meet the expectations of close family and health professionals for them to control blood sugar better.

In the experiential universe, participants construct and illustrate well-being from their own lived experience. The analysis of the classification tree revealed a discursive opposition between issues, both identity-related and emotional. Specifically, this lived experience is likely to be shaped by concerns related to participants' membership to adolescent and diabetic groups. On one hand, participants furthest from the glycemic objectives (i.e. glycated hemoglobin rate > 9%) were focused on the positive experiences characteristic of adolescent concerns, such as extra-curricular activities and sweet consumption. On the other hand, those closer to the glycemic objectives (i.e. glycated hemoglobin rate < 9%) were focused on negative experiences characteristic of diabetics, such as the capacity to act on treatments and the impact of diabetes on relationships to others.

The lexicometric analysis finally illustrates the important role played by self-management in the representations of well-being as well as in the tensions, which are likely to be associated. Self-management considered by health professionals as effective in controlling glycated hemoglobin rate can at the same time have a negative impact on the subjective well-being of patients. It is important to note here that discursive focalizations are not associated with the gender of participants, which means that discourses are common to both girls and boys.

Meanings of self-management: both facilitators and obstacles to well-being

The thematic content analysis provided an in-depth examination of the role of self-management in the discourse of participants. This analysis showed that the issues associated with self-management were spontaneously mentioned by 53.5 percent of participants when they spoke on the question of well-being. The link between self-management and well-being was viewed in accordance with two distinct meanings that were not associated with any variable (i.e. glycated hemoglobin rate and gender of participants).

The first meaning referred to self-management as facilitating well-being (21.4% of participants). Associated discourses focused on the benefits of effective self-management. This would avoid hypoglycemia and hyperglycemia, which are obstacles to psychological and social fulfillment. The extracts below illustrate this reasoning when the social psychologist asked participants what the idea of well-being means.

> It means being neither too high nor too low from a diabetes point of view, and doing what I have to do […] I have to be alright for football and all that. If I'm not well I don't go. (P9, 13-year-old boy)

> If everything's going well with my diabetes or not. When it's going well, that means I have a normal blood sugar level, and when it's not going well it means that I'm either hypoglycemic or hyperglycemic. (P8, 15-year-old boy)

> When my diabetes is under control, I feel okay. You can feel really great then. For example, when I'm hyperglycemic, I feel bad and compared with others it's obvious, mentally and physically. (P21, 13-year-old girl)

The second meaning referred to self-management as an obstacle to well-being (32.1% of participants). Associated discourses focused on the harmful effects of self-management. The most frequently reported elements referred to the repetitive injections of insulin and glycemic control, lived in a distressing or painful way, and that this led to certain sense of weariness. Some participants may feel embarrassed when they inject insulin in front of non-diabetics, but also frustrated when they are unable to adopt the same eating behaviors as their peers:

> There's times when I feel bad because I have to do my insulin, when I don't want to. […] It bugs me, insulin, I don't like injecting myself. (P2, 12-year-old girl)

> When I have to inject myself in front of everyone, I'm embarrassed, I look different to everyone else and I don't like it. (P10, 15-year-old girl)

> When I'm not allowed to eat sugar, I don't feel so good 'cos my friends, they can eat it. (P20, 16-year-old girl)

Parents and health professionals were also associated with this negative representation of self-management. Participants mentioned the repetitive injunctions issued by adults to achieve self-management behaviors, as well as their regular warnings about risks to health. Faced with the weariness of these discourses and the difficulty in complying, some participants said they paid less attention to it:

> It's not that I don't care exactly, but it's a bit like that you know. I'm a bit indifferent to it all. But I still try to improve some things. That said, I don't manage to, so what can I do? There's times when I say to myself "that's it I'm sick of it." […] My parents are always saying that I must pay attention to my diabetes, that I'm in danger of going blind later on, and having problems with my arteries and everything, and that that also applies to school because when I am hyperglycemic I can't concentrate. So there you are, I can't be bothered, it's exhausting. (P17, 16-year-old girl)

Finally, it may be that adolescents find the responsibility of self-management difficult to cope with. The fear of making mistakes in self-management behaviors and putting their life in danger can indeed be a great source of pressure for some participants, which may reduce the sense of personal capability. The following extract shows the discourse of a participant who represents responsibility for self-management as a danger to her own health in response to the empowerment process initiated by her parents.

> When the diabetes started, it was fine, my parents always talked to me […] I think they think I'm used to it now […] I'm frightened of not being up to it and putting myself in more danger. It wears me out because before I didn't have to do it, it's too complicated. (P7, 14-year-old girl)

Discussion

In line with the objective of exploring the social construction of meanings related to well-being, we used a combination of two types of analysis. First, a thematic content analysis allowed us to explore participants' common and shared discourses. The results showed that participants viewed and experienced well-being in a polysemous and multidimensional way: mainly, as physical health, psychological balance, healthy diet, medical recommendations related to diabetes, recreation which allows them to forget the stresses of diabetes, the ability to affect oneself or others, and socio-emotional relationships maintained with peers and family. Then, a lexicometric analysis allowed us to explore oppositions between studied themes and their statistical association with participants' characteristics. The results suggest that representations of well-being would be determined by participants' social membership as well as by the relationship maintained with self-management and glycemic objectives. Specifically, the expectations and needs expressed as a teenager are always likely to be upset by the injunctions to self-management received as a diabetic. For instance, participants who meet the expectations of health professionals and their glycemic objectives draw on negative representations and experiences of well-being. The meanings associated with diabetes' self-management would then play a decisive role in the emergence of tensions relating to these representations of well-being. This hypothesis, derived from lexicometric analysis, was examined in further depth by a thematic content analysis focused on the relationships between well-being and self-management. The results showed that some participants adhere to positive representations that adults can have toward self-management by considering it as facilitating well-being, while others seem to represent it as an obstacle to well-being. All things seem to indicate that well-being is an object marked by many areas of tension.

Well-being and self-management: polymorphic and tensional objects

The representations that give meaning to these lived experiences must be contextualized within a set of socio-symbolic relationships that shape identities and social existence (Jodelet, 2006, 2013). Therapeutic patient education can be seen as a socialization area where health professionals teach patients to think of their existence in terms of self-management governed by health-related logic (e.g. anticipating the consequences of their actions on their own health, planning their daily life in accordance with disease and associated treatments). This practice may be related to the ideological project of Western neoliberal societies that is characterized by the valuing and normalization of self-control, autonomy, and individual responsibility (Foucault, 2008; Joffe and Staerkle, 2007; Rose, 2000). However, this project is not something that necessarily comes naturally when it is contextualized within the subjective and social experience that diabetic adolescents may have of well-being. Such contextualization brings out "areas of tension" (Kalampalikis and Apostolidis, 2016) likely to affect the relationship that patients have with the disease and their social environment.

In our case, the areas of tension refer to the contradictory meanings that the different protagonists are likely to associate with the objectives of the therapeutic patient education. Although rational management of self can be considered by adults as a useful and valued skill to acquire, this objective appears to be understood and experienced differently by a number of our participants. Their discourse presents a readjustment of the meanings associated with self-management skills, the latter being perceived as an obstacle to their psychological and social well-being. More specifically, the mobilization of self-management skills for a chronic disease implies a strong orientation toward the future (Alberts and Dunton, 2008; Hall et al., 2012), that is, a responsible attitude focused on the achievement of therapeutic objectives. Self-realization through these neoliberal expectations is associated with the attribution of an adult identity (Arnett, 2006), whose social function aims at marking a symbolic break with the world of adolescence and irresponsibility (Bourdieu, 1992). Indeed, these expectations prove to be incompatible with the hedonistic attitude of some participants that veers toward carelessness and seeking immediate pleasure (e.g. choosing to share a very sweet diet with friends while knowing the risks related to this type of consumption). This way of thinking and experiencing well-being finds its socio-genesis in the axiological system of adolescence and shapes lifestyles and socialization between peers (Hamzah et al., 2014; Vrangalova and Savin-Williams, 2011). This attitude is opposed to that of a "mature" management of self as promoted by health professionals with a view to health optimization. The practice of the therapeutic patient education could thus be marked by the idea of emancipating young patients from their membership to the adolescent group so that they can adopt a way of being characteristic of an adult social identity. This hypothesis is supported by a comparative study showing that young adults with diabetes consider themselves as more adult than non-diabetics of the same age (Luyckx et al., 2011). In other words, the self-management skills that patients acquire and draw on are likely to not only engage them as diabetics but also as emerging adults.

The social representations approach allows us to grasp two types of practical functions associated with the way in which participants construct well-being in the context of the constraints experienced faced with the self-management of diabetes. First, expressive functions (Jodelet, 2008) that account for the close relationships between representations and socio-affective life (e.g. the valuing of hedonistic activities between adolescents and perception of self-management as an obstacle to well-being). Second, functions aimed at controlling the situations encountered (Jodelet, 1989), according to a conception that posits the subject as a protagonist guided by his representations (e.g. rejection of self-management and delegation of responsibility for diabetes to adults). The articulation of these two functions reinforces the idea that the issue of self-management not only associated with maintaining or improving health, but also with the socio-symbolic relationships maintained with others and membership groups. More specifically, some participants may perceive self-management as an obstacle to well-being because it is thought to be associated with the acquisition of an adult identity that is incompatible with the preservation of a socialization that underpins their adolescent identity. This interpretation highlights the social logics that can determine the rejection of autonomy in the face of diabetes: on one hand, maintaining the hedonistic nature of the relationships with other adolescents in a context of chronicity that encourages early entry into an adult world characterized by constraints and responsibilities; on the other hand, delaying this socio-symbolic change by delegating the burden of managing pathology to close adults for whom taking responsibility is a skill which forms part of their role. Thus, these considerations remind us that social logics are always likely to supplant health logics when individuals are faced with health problems (Apostolidis and Dany, 2012).

Future research should study these social logics more closely by considering therapeutic patient education as a practice determined by normative expectations from the ideological context of reference. It would be necessary to think of this normalization in relation to the identity and social development of the patients in order to better understand their representations and coping strategies toward the chronic disease. The transition period that marks the change from adolescence to adulthood in a situation of chronic disease provides fertile ground for exploring this issue (see Luyckx et al., 2011). For example, studies could explore the effects of self-management skills on the acquisition of an adult identity and examine in depth the consequences of this new identity on the well-being of young patients and the relationships maintained with health professionals.

Practical implications

The findings of our study show that the well-being of diabetic adolescents does not necessarily go hand in hand with the self-management behaviors that health professionals aim to strengthen. This gap between the expectations specific to each of the protagonists has several practical implications for improving the well-being of diabetic adolescents involved in therapeutic patient education.

First, the areas of tension that can be observed when the patient's representations of well-being are confronted with the normative approach of self-management exercised by adults (i.e. parents or health professionals) should be identified more systematically. Creating measurement tools specific to the representations of patients should allow us to diagnose and support the potential impact of self-management on their psychological and social well-being more effectively. Counseling could be a complementary approach to conventional educational interventions, more focused on strengthening self-care skills, in order to better support adolescents in the empowerment process. For illustrative purposes, Karlsen et al. (2004) have shown that group-based counseling in adults with Type 1 diabetes can improve psychological well-being and the quality of glycemia control. The authors explain these results by the fact that peer groups are helpful in strengthening psychosocial skills, such as problem-solving and decision-making, in order to cope with problems posed by diabetes.

Furthermore, the sense of self-efficacy is also an important psychosocial skill involved in the development of well-being. Indeed, it has been shown that beliefs in self-efficacy for managing emotions and interpersonal relationships help to improve subjective well-being in adolescence, namely, positive thinking and happiness (Caprara et al., 2006). The concept from Bandura's (1986, 2004) social cognitive theory, the sense of self-efficacy, is often assessed in psycho-educational interventions in diabetology (Colson et al., 2016b; Fonte et al., 2014). Bandura defines this feeling as the belief of the individual in his own abilities to adopt certain behaviors. This concept is envisaged in relation to three socio-cognitive factors that, in our case, would be likely to influence the well-being of young diabetics: the expectations of results related to the perceived effects of self-management on well-being, obstacles and the perceived facilitators of self-management, as well as personal goals involved in the quest for well-being and motivation for self-management. For instance, concerning the expectations of results, we have seen that participants who represent self-management as an obstacle to well-being relate more negative experiences and feel less able to manage the treatment than those who represent it as a facilitator. Therapeutic patient education programs could therefore use Bandura's theory in order to identify certain factors likely to promote both self-management and well-being of patients (as is the case for the cohort of this study, see Colson et al. (2016a)).

Finally, it is important that adolescents having the benefit of a therapeutic education have an opportunity to express what they expect of the program, the way that best suits them to develop their skills according to their representations of well-being, and how to evaluate these skills. However, health professionals have delivered the majority of therapeutic education programs that have been implemented in France, within budgetary and time constraints, without necessarily involving children and their families in the design, implementation, and evaluation of the program. The same applies to international programs of therapeutic patient education, where it is above all criteria of a medical rather than a psychosocial nature which are used for inclusion (Colson et al., 2016b) and for evaluation (Fonte et al., 2014). From this perspective, a qualitative study based on focus groups involving diabetic adolescents, their parents, and health professionals would allow us to draw on collective expertise in order to better conceptualize well-being and respond to specific expectations of each protagonist involved in therapeutic patient education.

Limitations

Our study has some limitations. The first is the difficulty adolescents have in expressing themselves in interviews, limiting our understanding of the meanings that they are likely to associate with well-being. It would be interesting to combine other methods in order to examine these discourses in greater depth and facilitate symbolic expression. One solution might be to get adolescents to express their views about the drawings they have produced or photos they have chosen to represent well-being (for an illustration of this approach with children, see Darbyshire et al. (2005)). The creation of focus groups could constitute an alternative or complementary method to the use of pictorial materials. This qualitative method favors social interaction between participants and encourages them to build on each other's comments (Krueger and Casey, 2008). Furthermore, from the social representations perspective, focus groups are considered as a communication space allowing for observation and analysis of the social dynamics at stake in the construction of representations (Caillaud and Kalampalikis, 2013; Kalampalikis, 2004; Lunt and Livingstone, 1996). Therefore, this theoretical and methodological combination would allow us to (1) overcome the difficulty in collecting the content of representations associated with well-being in diabetic adolescents and (2) examine the social processes involved in the production of these representational contents in greater depth.

The other limitations are inherent to the specificities of qualitative research. First of all, we did not use a triangulation of researchers in the data analysis. This strategy is important because it gives credibility to the qualitative approach (Denzin and Lincoln, 1998; Flick, 1992). It allows us to overcome a certain number of epistemological and methodological problems, such as the dependence of the analyses on the subjectivity of a single researcher, or else the risk of over-interpreting the data. However, we think that the qualitative and quantitative analyses we have combined also allow us to decide on the credibility of our results. Indeed, we observed a convergence and coherence between the representational contents revealed by the thematic analysis and those revealed by the lexicometric analysis. Our research thus seems to meet the criterion of credibility as defined by Charmaz (2006), that is, the presence of logical and consistent links between the data and the results of the analysis. Finally, the sample size does not allow the data to be generally applied to the entire population studied. However, in terms of transferability of data (Jodelet, 2003), our results are relevant for interpreting comparable situations of therapeutic education in different populational and pathological contexts. Many chronic diseases diagnosed during childhood or adolescence share the same health and psychosocial issues as Type 1 diabetes. They involve the need to draw on self-management skills that are always likely to create areas of tension which could negatively impact the psychological and social well-being of adolescents.

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Notes

1. A software developed by Pierre Ratinaud (http://www.iramuteq.org/).
2. This is a French expression that refers to the idea of feel good about yourself.

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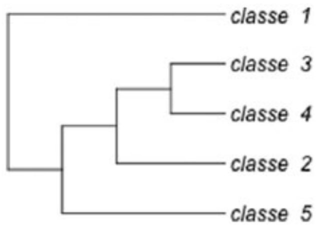
Appendix 1

Table 2. Visualization of the steps of lexicometric analysis through a section of our results.

Steps of analysis	Illustration with class 1	Extracts from the analysis report
1. Identification of variables and words associated with the class.	The analysis report shows all variables and words associated with class 1. For instance, participants who have a glycated hemoglobin rate above 9% are significantly associated with this class. The words "health," "skin," and "eating" are also significantly associated with this class. In contrast, the word "problem" has to be excluded by the researcher because it is not significant.	Variable — χ^2 Glycated hemoglobin rate > 9% — 4.57* Word — *N* in class — *N* total — χ^2 Health — 16 — 18 — 49.52*** Skin — 9 — 10 — 26.51*** Problem — 5 — 11 — 3.18 Eating — 4 — 4 — 13.35***
2. Semantic contextualization from the extracts from where these words were derived.	The analysis report shows the extracts of the corpus from which the significant words of the class are derived. It allows each word to be contextualized and its meaning to be interpreted. For instance, when the word "skin" is contextualized, it refers to the idea of well-being as a state where you feel good about yourself (literally in French: feel comfortable in one's own "skin").	P7: "well-being means feeling good inside, feeling good about yourself" P22: "when I'm having a laugh, I feel good about myself" P16: "feeling better about yourself and having a balanced diet" P23: "feeling great and good about yourself, not… well, I don't know really"
3. Grouping the words into specific sub-themes and attribution of a general theme to the class.	Once semantic contextualization allowed the meaning of words to be assigned to class 1, they are categorized into different sub-themes. A general theme was then defined based on all sub-themes. For instance, the word "skin" was categorized in the sub-theme "self-acceptance" with other words of this class that had a similar meaning, and the general theme of this class was named "health and nutrition."	General theme • Health and nutrition Sub-themes • Good physical health (e.g. "health") • Happiness and cheerfulness (e.g. "happy") • Absence of disease (e.g. "disease") • Self-acceptance (e.g. "skin" and "body") • Balanced diet (e.g. "eating" and "balanced")
4. Giving meaning to the relationship between each class from the top-down hierarchical classification.	The analysis report shows a dendogram representing the top-down hierarchical classification. It helps us to understand and interpret the discursive oppositions between lexical classes once the first four steps of analysis have been performed for these classes. For instance, class 1 is opposite to other classes according to a specific discursive logic. Representations of well-being are constructed through common sense and medical knowledge in the first, whereas well-being is constructed from lived experience in the others.	

*$p < .05$; ***$p < .001$.