



Patient Perception, Preference and Participation

The narrative-autobiographical approach in the group education of adolescents with diabetes: A qualitative research on its effects

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ABSTRACT

Objective: To introduce a narrative-autobiographical approach in the care and education of adolescents with type-1 diabetes and observe the effects of this novel approach on adolescents' self-awareness, concern for self-care, and well-being.

Methods: Ninety-four adolescents with type-1 diabetes attending one 9-day summer camp in 2004, 2005, or 2006 participated in structured daily self-writing proposals on diabetes, integrated with daily interactive self-management education. After some months, we sent participants interview-like questionnaires, and two independent researchers performed a qualitative analysis of the 50 answers that were mailed back.

Results: Writing about the discovery of diabetes was, for many, a stressful experience, but with a strong liberating effect. One relevant point was *change*, which occurred: (a) in the perception of self; (b) in the relationship with others; (c) in the relationship with the disease.

Conclusions: The integration of autobiography in diabetes camps, by adding the value of sharing individual stories to the liberating power of self-writing, can allow the adolescents to overcome their feelings of diversity, and can initiate several changes reflecting increased self-efficacy, maturity, acceptance of the disease and responsibility in self-management.

Practice implications: Self-writing is feasible and well accepted, and provides healthcare professionals a proper way to patient-centered care.

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1. Introduction

In recent years, patient education for the self-management of diabetes and chronic diseases has undergone considerable changes; it is no longer directive and not merely informative, as in the past, since we are now aware that adopting a healthy habit depends less on information and skills than on personal intrinsic motivation to change [1].

Having focused on motivation to change, healthcare professionals dealing with chronically ill patients have adopted several models based on behavior science to understand and facilitate

behavioral change: e.g. the trans-theoretical model [2], the social-cognitive model [3], motivational interviewing [4], active listening [5], empowerment [6], and several of these have been included in broader conceptual frameworks conceived for improving the quality of chronic disease care, such as the chronic disease model [7] and patient-centered care [8].

Establishing a therapeutic alliance appears especially difficult with adolescents with type-1 diabetes, who – like those with other chronic conditions – “are doubly disadvantaged, engaging in risky behaviours to at least similar if not higher rates as healthy peers, while having the potential for greater adverse health outcomes from these behaviours” [9]. They often display a degree of carelessness towards diabetes, with consequently far from ideal glycemic control [10,11], and possible early appearance of micro-vascular disease [12]. An effective education would therefore appear particularly useful for children and adolescents, but,

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Table 1
Number and characteristics of adolescents and health professionals participating in the summer camps, and number of returned questionnaires.

	2004	2005	2006
Number of adolescents	30	38	26
Gender	18 m/12 f	17 m/21 f	16 m/10 f
Age (years)	16.5 (range 15–18)	16.1 (range 13–18)	16.0 (range 14–18)
Duration of diabetes	6.2 (range 2–14)	6.2 (range 2–15)	6.0 (range 1–15)
Questionnaires received (%)	6 (20%)	25 (66%)	19 (73%)
Personnel	4 MD, 1 RN, 2 Educ, 1 Trainer	6 MD, 2 RN, 2 RD, 2 Educ, 1 Trainer	6 MD, 1 RN, 2 Educ, 2 Trainers
Trainees	5 MD, 1 RN, 3 RD, 2 Psychologist	6 MD, 5 RN, 1 RD	5 MD, 6 RN, 1 Psychologist

despite multiple efforts, the results are generally inconsistent and unsatisfactory, as summarized in two recent comprehensive literature reviews [13,14], which conclude, discouragingly, that there is still insufficient evidence to recommend any particular education program. Even a recent RCT based on the social-cognitive theory showed partially positive results on glycemic control, but, quite astonishingly, no effect on reported adherence behaviors [15].

Because emotional disorders are clearly associated with poorer health outcomes, it appears that emotional regulation is a key healthcare target even when diabetes self-care is adequate [16]. In our previous experience of care and education in diabetes summer camps, however, adolescents appeared particularly resistant to revealing to themselves and to others their inner feelings and real concerns.

The narrative-autobiographical approach, introduced as an educational tool first in the humanities [17] and then in medicine as a component of “Narrative-Medicine” [18], determined a thorough evolution in the concepts behind the education and care of people with chronic diseases. It is the educational means by which, through the use mainly of self-writing, one’s life-history can be discovered, explored and interpreted by recalling episodes and experiences that are part of one’s identity [19]. In a narrative perspective, the disease, especially a chronic one such as diabetes, represents a breakdown that not only imposes changes in day-to-day life, but also poses questions regarding the sense of the existence of the individual, thereby affecting quality of life and subjective well-being, spoiling one’s future perspectives and plans. To cope with the problem, the person must understand the experience of being ill, finding and assigning meaning to the condition. Sick individuals must realize and reinterpret their story, their world and their life [20].

The autobiographical approach has proven effective in helping people to reveal, first to themselves and then to others, their needs and feelings related to their condition [21]. Moreover, the possibility of sharing one’s stories with a group of peers may add an important value to the individual self-care provided by writing for one’s self about one’s self.

We therefore adopted this approach with adolescents with type-1 diabetes. Our aim was to observe, using qualitative research, whether a structured autobiographical approach was feasible and welcome in the setting of summer camps with diabetic teenagers, whether this approach could stimulate participants’ self-awareness and understanding of others, and, eventually, whether these changes were associated with increased participants’ interest about self-care and with their well-being. We also aimed at understanding the significance of different autobiographical activities for adolescents with diabetes.

2. Methods

2.1. Context

The narrative-autobiographical approach was used during three 9-day summer camps that were run at the end of June in

2004, 2005 and 2006. The location was a small hotel either in Sardinia (2004, 2005) or in Abruzzo (the mountain region near Rome, 2006). The number of participants and their characteristics are shown in Table 1.

The healthcare team that organized and ran the camp is shown in Table 1. Furthermore, several health professionals working in diabetes (*trainees*, also shown in Table 1) attended a master course on therapeutic patient education, which consisted in participating in all educational activities with adolescents, being available in teams to help teenagers in self-management upon request (three–four children per team), attending one 1-h lesson per day, and reporting and discussing management problems at post-dinner meetings.

2.2. Sampling strategy

The adolescents were enrolled in their respective diabetes units (in general, pediatric diabetes units) on a voluntary basis, upon invitation by the medical team to the family. ADIG-Lazio and GED-Sardinia cooperated in distributing information about the camps, and organized pre-camp meetings where the organizers met the candidates and their parents. The criteria for admission to the camp were: age 13–18 years and having diabetes for at least 1 year; having problems in the self-management of diabetes; agreement to participate in the narrative-autobiographical itinerary. No socio-demographic data were considered. In general, a maximum of three teenagers were accepted from each diabetes unit.

2.3. Daily educational activities at the camp

Morning: physical activities or sport games. Afternoon: (a) 2 h, autobiographical approach; (b) 1.5 h, diabetes self-management education. Although different people were responsible for the planning and implementation of the two approaches, we made an effort to integrate the narrative and the scientific approaches and methods.

2.3.1. Implementation of the autobiographical approach

Each day we suggested one topic to participants for writing. We then shared the writings by reading them in plenary; anonymity was ensured to avoid difficulties, embarrassment, fear of being judged.

To facilitate and support self-remembering and narrative through writing, we associated/integrated other communication tools, such as songs, poems and readings, along with other techniques of self-expression, such as choosing images, drawing and creative workshops.

The list of all self-writing proposals is shown in Table 2. We used a gradual step-by-step approach, starting with micro-writings about needs and expectations and spot mosaic writings allowing the self-introduction of participants to create the appropriate narrative atmosphere in the group. We then tackled some of the daily challenges of living with diabetes, selecting those which, according to our experience, are the most frequent concerns of adolescents, i.e. each one’s relationship with food, with one’s

Table 2
The autobiographic journey.

	Workshops and subjects for writing and discussion	Scores mean \pm SD
Day 1	Why am I here?	5.8 \pm 2.4
Day 1	What I need and desire from the summer school	6.2 \pm 1.9
Day 2	My life-history: the interview	7.3 \pm 2.0
Day 3	Shapes of body: let us speak of ourselves by our bodies (2004)	6.5 \pm 2.6
	Creative Workshop: express yourself by creating a mask (2005)	7.1 \pm 3.1
	Let us cultivate (and draw) a small plant as a metaphor of care (2006)	7.3 \pm 0.7
Day 3	One word to describe diabetes	8.0 \pm 1.9
Day 3	"Fragments" of writing about myself	8.0 \pm 2.1
Day 4	My diabetes and how it affects my relationship with food	7.1 \pm 1.7
Day 5	"The day when I first discovered I had diabetes"	9.5 \pm 1.0
Day 5	An image for diabetes	7.6 \pm 1.1
Day 5	My diabetes and how it affects my relationship with others (parents, friends, girlfriend/boyfriend, teachers, school-friends, relations, doctors and society in general)	8.4 \pm 1.4
Day 6	Listening to the stories of others	9.1 \pm 1.4
Day 7	A message in a bottle (SOS) (in 2004 only)	8.7 \pm 1.2
	"Dear Mask, I am writing to you..." (in 2005 only)	7.2 \pm 3.0
	"Dear Plant, I am writing to you..." (in 2006 only)	7.5 \pm 0.7
Day 8	The meaning of this summer school	7.9 \pm 1.8

Suggested workshops and subjects for writing and discussion during camp days (from 1st to 8th). The average scores ($n/10$) given by adolescents in response to question No. 2 (Table 5) \pm standard deviation (SD) are shown in the last column, indicating how much each activity has been significant for them.

own body, with others, with self-care. Only on the fifth day did we engage in one of the most complex proposals of self-writing, namely the recall of the day when diabetes was discovered, which, for many, is a painful experience and seldom worked through, and, thus, often blocking the acceptance of the disease and its proper care. A few examples of adolescents' writings are shown in Table 3.

2.3.2. The self-management education program

The overall educational strategy was based on the empowerment or patient-centered approach [16], and all healthcare professionals agreed to refrain from any prescriptive or persuasive attitude. The adolescents were encouraged to be free in the self-management of their insulin doses and food uptake, and they were

only asked to provide any information they might have about their blood glucose control to their reference team of trainees, "because this information is part of our training and is going to be used in our daily meetings." The trainees were instructed to encourage problem solving, but only when advice was requested.

Formal educational activities were limited to 1.5 h per day. The topics are listed in Table 4, together with the methods adopted, and included all relevant aspects of diabetes treatment. From day 1 to day 5 the objective was to let participants acquire the necessary skills in insulin dosage and carbohydrate adjustment under all circumstances, including physical exercise of various durations and intensities, and also to provide novel information when necessary. No particular monitoring or treatment scheme was

Table 3
Examples of adolescents' writings at summer camps in various moments of the journey.

Needs and desires (day 1)
I need someone who can understand me and with whom I can share what other people don't want to hear.
I'm here because at this time I need to have contact and an exchange of views with people who are in the same situation as I am and who might understand me better.
I need to understand better what is happening to me.
Wishes?! I have many. The most important one? Impossible. Another one: feeling "normal". In some degree diabetes limits me.
I hope I can somehow feel normal again, I'm not saying I feel different, but sometimes people's ignorance makes me uneasy, and it is only during these camps that I get to meet many other people who can see and understand my point of view.
The day when I first discovered I had diabetes (day 5)
I didn't want to admit to myself what had happened to me. The confirmation, the harsh and sad reality came all of a sudden; maybe I wasn't ready, it arrived when I had to give myself my first injection. And then I didn't cry anymore, nor did I relieve my feelings, I kept all the sorrow inside of me.
Accepting it straightaway was forced; I had to! But inside of me, this acceptance has never been full. I can smile when I talk about it; I can say I accept it, but I lie when I do, not to myself though, but to the others.
I can't feel like people who don't have diabetes; society itself sets us limits. I can't either consider diabetes a friend, talking is easy for those who are not in our situation. You choose your friends, friends don't set you limits.
Unfortunately and despite my trying, I haven't been able to accept diabetes, and this very often devastates me, although I rarely let it show, because I don't want my close ones to worry about me.
When people ask me: 'How did you take it when you found out you had diabetes?', I answer I don't care at all, but it's not true because I believe such things can never be accepted, especially when you're surrounded by people who don't know what that means.
Dear Mask (Day 7)
Dearest,
How many times have I searched for you. In the middle of the night when, paralyzed with the fear of losing my way, of never finding the way home again, my only true comfort was you, my guiding star. Your never-ending brilliance, your constancy and your being there have always reassured me when I'm looking for certainty.
True, sometimes you are hidden, but I know you have not disappeared, that you will not desert me, that you will reappear if I know where to look.
It has happened that, at times, you were not in the same place as I, but I only have to move to find you again: in the infinite sky you are always there. Each time that I have found you again, you have given me the strength to carry on along the interrupted road, which, illuminated once again, seems more beautiful than before, and the desire to go along it more intense. I'm leaving you with thanks that you exist, and if, one day, you become a shooting star, I shall be ready to make my wish.

Table 4
Topics for the self-management education program and methods adopted.

Day 1	Hypoglycemia, practical issues	Metaplan [®] , 3 groups
Day 2	Insulin, the rules	Work in 6 small groups
Day 3	Management issues during day-long physical activity	Discussion in plenary
Day 4	Nutrition 1. Estimate of weight of servings	Exercise, 2 groups
Day 4	Exercise on carbohydrate counting	Buffet dinner
Day 5	Nutrition 2. Estimate of carbohydrate content of servings	Exercise, 2 groups
Day 5	Exercise on carbohydrate counting	Buffet dinner
Day 6	Relationship with others	Role-playing
Day 7	Questions and answers	Plenary

suggested. The methods used were interactive 90% of the time, and exchanges of opinions and solutions were encouraged to favor peer-to-peer learning. On day 6, we dealt with a range of “social” issues, on request, including any possible limitation associated with having diabetes. On day 7, we dealt with “special” topics, on request, such as pregnancy, chances of transmitting diabetes to children, risk of diabetes complications, and risk of addictive

behaviors, always keeping a reasonably optimistic and non-judgmental attitude.

Formal group education was also the moment when we dealt with any biomedical issues that might have arisen during the autobiographical activity, always adopting a maieutic attitude. In this way, we implemented an integration of the two approaches.

2.4. Qualitative research about the autobiographical approach to the education and care of people with diabetes

To understand the educational and therapeutic value of integrating the autobiographical approach with the other various interventions, we wanted to analyze the reflections and experiences of the youth who had attended our camps. Therefore, in December 2005 (18 months after the first camp and 6 months after the second), we mailed to all participants in the 2004 and 2005 camps a semi-structured questionnaire consisting of 12 open-ended interview-like questions about the camp and the self-writing experience, and 1 question asking to score the various activities on a scale of 1–10, with 1 = least impressive and 10 = most impressive (see Table 5). In order to verify whether a

Table 5
The semi-structured questionnaire. Question 2 is the only partially closed question, including the list of activities shown in Table 2 and, for each, a score on a scale from 1 to 10.

1. After a period of time, what are your most significant memories of your experiences at the Summer Camp and why?
2. For you now, how significant are the several proposals we suggested at the camp, and why? Please mark on a scale from 1 (=least impressive) to 10 (=most impressive) how impressive each activity remains for you [The list of workshops follows].
3. Do you remember any of the feelings and emotions that you experienced while you were writing at the camp?
4. Do you think that, by using the Autobiographical Approach, your way of living and thinking and your perception of your life-history have been influenced, and, if so, in what way?
5. Do you feel changed by your experience at the camp, and, if so, in what way?
6. In particular, because of your experience at the camp, has anything changed in your relationships with others?
7. Have you written anything more about yourself following the experience of the autobiographical exercises at the camp?
8. Has anything changed since the camp in your relationship with your diabetes?
9. If we ask you again now for one word or an image to describe your diabetes, what would be your answer?
10. Has anything changed since the camp in the self-management of your diabetes?
11. When you have to make a decision concerning the self-management of your diabetes, can you recognize any lasting influence from the camp – if so, what?
12. What are your hopes for the future?
13. Do you have anything to tell us which was not covered by our questions or have you any comments or suggestions for future camps?

Table 6
An example of the content analysis of elicited texts. Only a few examples of conceptual labels are shown, and all the categories that contribute to one macro category.

Conceptual labels	Category	Macro-category
“At start slightly uncomfortable... then easy”	Embarrassment, shyness	
“I remember some shyness and shame, but then courage and the strength to go on”		
“It was a very pleasurable experience”	Enjoyment and well-being	
“In general, I also enjoyed (a bit) telling about myself”		
“The most profound emotion I felt was the freedom to write things about myself without feeling embarrassed and without inhibitions”	Writing liberates	
“I felt free”		
“Through writing I immediately experienced each emotion I recalled”	Writing makes you relive your pain	Initially, the writing proposals induce confusion, discomfort and shyness in revealing to others such intimate parts of the self.
“What I felt was sadness and anger because memories are painful when recalled”	Hearing one’s own story is a new experience	it frees and generates happiness and well-being. After some time, the memories of the writing experience remain strong and positive, as if re-living suffering, as well as the experience of listening to one’s own and to others’ stories, is a necessary step to care.
“I was moved in hearing some of the writings ‘that day when I discovered I had diabetes’. Mine made me weep”.	generating great emotion	
“It was even more moving to hear my story being read during the sharing of writings”	Writing appears in its ambivalence, as a process that, through re-actualization of suffering, may become care	
“You got to make me weep and then to make me rid myself of a weight I didn’t think I had inside me...”		
“Feelings have been very strong, I shivered for the rest of the day; negative thoughts surrounded my mind, but then, thinking better, it was very good for me”		
“To me, that moment was unforgettable, even if it hurt me a lot to relive certain moments”		
“Whichever letter you read, by anyone, tears came out of my eyes by themselves! This was a fantastic emotion, but sad at the same time”		
“When they read those letters about ‘the discovery of diabetes’, that was one of the worst experiences in my life... maybe it taught me something”		

Table 7

Examples of semantic units and categories showing change in the perception of one's self or in the relationship with others.

Self-esteem and confidence
"Many things have changed with my parents, with friends... I feel more self-confident"
"I am more convinced about my decisions"
"Before I was afraid of everything, but, after this nice experience, I cheered up, and I feel changed"
"I feel changed inside; I am more willing to go on"
Maturity
"Everything had an important meaning, and it helped me to grow and to understand"
"I feel more mature from all points of view"
"Certainly it was important for me. These are experiences that do not happen everyday, and they help you to grow not only physically, but, most of all, mentally"
No more embarrassment or shame
"I feel more extroverted"
"I can give much clearer replies to those who ask me what I am wearing (the insulin pump)"
"Now I feel better when I am with others"
"Now I feel more secure and less concerned about the thoughts of others seeing me self-inject insulin or taking some sugar sachets"
"Less shame in saying I have diabetes, when it's needed"

saturation of categories had been reached, in December 2006, we mailed the same questionnaire to the participants in the 2006 camp; because no additional themes appeared, we considered the sample size sufficient.

Because the only contact information we had for participants was their home addresses, we sent paper questionnaires by mail. To encourage freedom of expression, we did not ask them to sign questionnaires. To increase the response rate, we sent a reminder to all participants 2 weeks after the first mailing.

Table 8

Examples of semantic units and categories showing change in the relationship with diabetes.

Accepting the illness
"I went through a denial of the disease, but now that's over"
"Thanks to the camp, coming in touch with people having my same problem, I managed to accept it, even if with difficulty, because now it's part of my life, it's part of me"
"Now I am at peace with myself"
"I started to come to terms with it and to stop thinking, Why just me? Well, since it happened to me and to so many others, we must learn to accept it and to live with it"
"I am even more convinced that we can live even better, just as those who don't have it"
"My relationship with diabetes has changed; it is more peaceful now maybe also thanks to a natural evolution of the acceptance of the disease"
"I accept it more and don't consider it an obstacle any more"
A new perspective on the illness
"It makes you look at the world of illness in a different way"
"Before I felt it as an enemy and kept it at a distance pretending it didn't exist because I didn't want to accept it. That's why I ate anything I wanted and ignored the levels of glycerin"
"Before I felt a certain anger and negativity in facing up to it, this has now been removed"
Responsible attitude
"Now I try not to worry too much about it, to give it a certain importance, to take the best possible care and always to have regular checks because I really care about my health"
"After the summer camp I am more careful and reasonable in what I do"
"I take care of my diabetes in a more aware and responsible way. Before the summer camp, I took care of myself because I HAD to; now I do it because I want to be well and not suffer the consequences in the future"
Becoming independent
"Before I did what they told me; now I do what I need"
"At the summer camp, I improved particularly in my way of balancing the food with the insulin, regulating when I have to eat either more or less or in a different way, trying to avoid hypo- and hyper-glycemia"
"I became more independent after the summer camp"
"Now I decide how much insulin to take, relative to the carbohydrates that I eat, without leaving this decision to my parents"
The therapy
"It helped me to understand and accept that the pump was not what I had thought: a heavy, invasive apparatus, but, in fact, a useful way of managing my diabetes, and, for this reason, after 2 weeks, I decided to try this new system"
"Less than a month after the camp, I started to use the pump"
"I learned to adjust treatment mathematically, following also some formulas I have seen at the camp"

The elicited texts were subjected to content analysis, in analogy with the data analysis of the "grounded theory" method [22], by extracting semantic units from the writings through a process called "conceptual labeling", and grouping them into various categories by a process of understanding and interpretation. The categorization and grouping were accomplished by one of us (NP), for 2004 and 2005 under the regular supervision of her doctoral tutor. The analysis was then systematically repeated by an independent educator (GR) and, whenever a difference in labeling or categorization arose, a confrontation of opinions was performed by the two until they reached agreement. An example of the conceptual labeling and categorization of answers is shown in Table 6.

3. Results

The number (and percentage) of questionnaires received per year is shown in Table 1. Overall, we sent out 94 questionnaires and received back 50 (53.2%), with a substantially lower response rate in 2004 than in 2005 and 2006.

Table 2 reports the scores given by adolescents to the different writing experiences. Among the proposals repeated in all camps, those which received the lowest scores (with a relatively large variance) were the ones for the first day. The most significant proposals remain those linked to the discovery of diabetes, which were almost unanimously judged the most impressive (highest scores and relatively small variance).

The analysis of texts generated 771 conceptual labels (12732 words), which were grouped into 61 categories (628 words) and 16 macro-categories (1406 words).

Table 6 reports, as an example, the analysis of the comments about feelings and emotions linked to self-writing elicited by question 3 (Table 5). The 74 conceptual labels (of which only 15 examples are shown) were grouped into six categories, which

contributed to building a theory according to which self-writing about diabetes appears to be an ambivalent experience, ranging from only positive to only negative feelings for few adolescents, while including a different mix of both components for the great majority of them.

Self-writing was also described by 65 semantic units as a tool facilitating: (1) self-reflection and introspection, (2) knowledge of others, (3) new learning and self-awareness, (4) re-construction of one's own story, (5) response to a need, (6) relief, and (7) distancing from sad feelings.

A relevant point emerging from the questionnaire is *change*, which, for many participants, occurred in three directions.

- (1) Change in the perception of one's self: adolescents increased their self-confidence and trust in their potential. Based on 35 semantic units grouped into 4 categories (Table 7).
- (2) Change in the relationship with others: they overcame obstacles and shame to make their diabetes known to others. Diabetes has become an issue of sharing and confrontation at home and with friends. The fear of not being accepted is over. Based on 32 semantic units, 2 categories (Table 7).
- (3) Change in relationship with the disease: diabetes is better accepted, has become "a piece of the self", its representations and relative feelings are more positive, and its daily management has become a more independent and responsible practice. Based on 137 semantic units, 7 categories, and 2 macro-categories (Table 8).

Written comments were also helpful in explaining some "strange" scores. For example, one participant scored 1 on the activity with masks and wrote: "I did not make any mask because I have worn a mask all life long, for years". Another explained that he/she had scored 1 on all activities of the first days because he/she had forgotten them. Only one participant scored 1 on the sharing of self-writings about the discovery of diabetes and suggested that we not share those any more "because everyone has suffered that day, more or less, and it is not a nice thing to do", and concluded: "As to the rest, compliments, you have been very good. Kisses".

4. Discussion and conclusion

4.1. Discussion

We introduced the narrative-autobiographical approach in diabetes education, as a support and integration of biomedical care, and we adopted a qualitative research paradigm to understand the meaning of our approach in the lived experience of adolescents with diabetes. Consistent with this paradigm, the results we have obtained are narrative, and they can tell us which constructs of meaning recur and with which behaviors they may be associated, but not with which frequency they appear, nor any causal relationship.

Our choice is supported by a growing concern expressed in the literature about the appropriateness of quantitative research alone in understanding the perspectives of patients [23] and was confirmed by some inconsistency in the scores, ranging from 1 to 10 both by and between participants. This would have been frustrating in a purely quantitative perspective, but was often well explained by the accompanying open answers.

Typical of qualitative research is to remain "open". No theoretical construct can ever be considered as finally shaped, and the process of generating theories can never be considered as ended.

The content analysis of texts has made us fragment the participants' replies in semantic micro-units, thus losing the vision of each individual's entirety in favor of a theoretical choral re-

construction of the group. This is an unavoidable limit of a method aiming at finding common themes by a multiple-eye, cross-sectional reading of texts. Therefore, it has been difficult to relate some effects to specific causes: namely, in general it is impossible to assign the described changes specifically to the self-writing activities. It seems more likely that the changes were due to the integration of the narrative-autobiographical and the medical approaches, resulting in a novel educational style, open to the listening and respect of each individual and to the encouragement of the possibilities of each life-history present at the camp.

One weakness of this study is the fact that almost half of the questionnaires we sent out were not sent back. As the lowest response rate was obtained from the 2004 group (20% vs 69%), we think that the longer time gap (18 months vs 6 months) might have led to lower adherence to the survey.

4.1.1. Comparison with other studies

To our knowledge, this is the first study on the use of the narrative-autobiographical approach, including expressive writing, with adolescents with type-1 diabetes.

The power of writing to reveal thoughts and feelings otherwise difficult to express orally has long been known. The possible therapeutic effect of written emotional disclosure, first described more than 20 years ago [24], has been studied in adults with several chronic diseases [25–34] and also in adolescents with asthma [35], mostly with positive results, sometimes limited to some aspects, either physical or psychological.

An important difference with our study is that, since the beginning, written emotional disclosure consisted mainly in writing about *any* emotionally significant fact, and this has also allowed a number of studies to be performed with healthy individuals. In our opinion, focusing on a strong emotional aspect *of the current disease*, like the day of its discovery, may have a more relevant impact. While the liberating effect of general emotional disclosure may be expected to be general, in our instance, it was reasonable to anticipate an effect more directly linked to diabetes and to the acceptance of its consequences in terms of life changes, responsibility, self-management, etc. For many, this was indeed the case, as shown in Table 8, without, through this, excluding the biological effects of emotional discharge, still possible and particularly relevant in case of diseases such as diabetes, for which persistent stress may be a cause of imbalance.

As previously described both in adults [29] and in adolescents [35], written emotional disclosure was associated with negative feelings in some participants. In fact, the well-known liberating power of re-living negative emotions is one of the reasons that prompted us to adopt the autobiographical approach. Indeed, all but one of the participants in the survey recalled a sense of well-being and of liberation, at different intervals after the camp.

In the only previous study using expressive writing with ill adolescents [35], individual solitary disclosure at home was chosen because writing in group settings "may have reduced effects due to social distractions, whereas solitary disclosure may be more powerful". Contrary to this assumption, we believe that, in our study, writing in a group – which was always done in a focused atmosphere – gave an added value to writing, because it offered the opportunity to share each individual story with all.

4.1.2. Unanswered questions and future research

Despite the positive results observed, several questions remain unanswered.

This qualitative study, by its nature, cannot answer questions such as how many changes were induced by the autobiographical approach, in which percentage of patients, or by which mechanisms. Further studies are needed to quantify effectiveness and to establish causal relationships between different interventions and

the resulting changes. To answer these and similar questions without losing the richness of the qualitative approach, an integrated quantitative–qualitative research is indicated [36].

The non-adherence to the study by almost half of the participants raises the question whether negative feelings may have been concealed, and, although this seems unlikely given the freedom with which criticism has been expressed by some participants, the clarification of this aspect would require further research.

Although not examined in this study, many healthcare professionals who attended the camps were enthusiastic about the use of autobiography with adolescents, because, for the first time, they saw adolescents unveil their inmost feelings, opening up within themselves and with the group, finding a new meaning for their disease and their life; this experience represented an important change also for their professional activity. The same impression was given by the adolescents' parents at two follow-up meetings a few months after the camps, where several "spontaneous" positive behavioral changes were reported. Obviously, these important aspects deserve more research.

4.2. Conclusion

Writing about one's self and one's own story appeared to be feasible during a summer camp and was highly appreciated by adolescents with diabetes, helping some of them to develop self-awareness, self-training and the continued discovery of innermost feelings. For many, it represented a safety valve, an outlet for the distress and sorrow accompanying the disease.

Sharing the individual writings within a group was, for the adolescents, an important occasion of mutual comparison and exchange, allowing some to overcome the feelings of loneliness and separateness accompanying the disease.

Many of the resulting changes described by adolescents after the camp reflect an increase in self-efficacy, maturity, acceptance of the disease and responsibility in self-management; all factors contributing, by definition, to a better quality of life. This is a therapeutic goal on its own, and, moreover, it has reportedly been associated with healthier behaviors [16].

4.3. Practice implications

This project represents a concrete implementation of the biopsychosocial model of chronic care [37] and restores the humanistic vocation of patient education, suggesting that the complexity of chronic disease can be managed by integrating the narrative and the biomedical views.

Attentive, empathic listening to patients' stories is an essential part of the current approach to patient-centered chronic disease care, in particular to diabetes care [5–7,16]. The use of self-writing makes patients' self-expression an easily reproducible and exportable method, and listening to peers' stories in a group adds an important value to self-expression. The ease with which adolescents, in the course of our camps, poured, onto a white sheet of paper painful memories and sad emotions that they would not reveal otherwise while under the "social control" of the group of peers, made us hope to have found a key to adolescents' (self)-care.

To start from life stories has allowed us to build a theory about living with type-1 diabetes and may help clinicians and policy-makers understand the lived problems and difficulties of adolescents with type-1 diabetes, which often have little to do with blood glucose values, but nevertheless can strongly influence them.

The narrative-autobiographical approach appears to be a proper way to patient-centered care. In fact, it puts the patient's self-writing at the center, and the writing becomes both the

transfer vehicle and the story container for the care relationship, allowing healthcare professionals to approach the patients' expression of painful feelings. However, for an effective practice, the human and relational attitudes of healthcare professionals, which have not been duly considered in education research [38], should be integrated with specific educational skills on, e.g. the choice of the writing path, the timing and method of its implementation, the decision about the proper moment to deal with traumatic events, the creation of decompression moments.

Applying this approach in diabetes camps with adolescents appears particularly relevant, but there are possible indications for broadening the interest of this study to the care of diabetes at large and, more generally, to the care of other chronic diseases. Indeed, the autobiographical approach can help any individual come to terms with being ill and foster motivation to make changes.

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