



## RESEARCH ARTICLE

# The Experience of Psychiatric Care of Adolescents with Anxiety-based School Refusal and of their Parents: A Qualitative Study

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## Abstract

**Objective:** Anxiety-based school refusal in adolescence is a complex, sometimes difficult to treat disorder that can have serious academic and psychiatric consequences. The objective of this qualitative study was to explore how teens with this problem and their parents experience the psychiatric care received. **Methods:** This qualitative multicenter study took place in France, where we conducted semi-structured interviews with adolescents receiving psychiatric care for anxiety-based school refusal and with their parents. Data collection by *purposive sampling* continued until we reached theoretical sufficiency. Data analysis was thematic. **Results:** This study included 20 adolescents aged 12 to 18 years and 21 parents. Two themes emerged from the analysis: (1) the goals of psychiatric care with two sub-themes, “*self-transformation*” and *problem solving*; and, (2) the therapeutic levers identified as effective with two sub-themes: *time and space* and *relationships*. **Conclusion:** Our results show a divergence between parents and teens in their representations of care and especially of its goals. Therapeutic and research implications about the terms of return to school within psychiatric care and also the temporality of care are discussed.

**Key Words:** school refusal, adolescents, qualitative research, child and adolescent psychiatry, patient reported outcome

## Résumé

**Objectif:** Le refus scolaire anxieux à l'adolescence est un trouble complexe, parfois difficile à traiter qui peut avoir de sérieuses conséquences scolaires et psychiatriques. Cette étude qualitative a pour but d'explorer comment les adolescents aux prises avec ce problème et leurs parents ressentent les soins psychiatriques reçus. **Méthodes:** Cette étude qualitative multicentrique a eu lieu en France, où nous avons mené des entretiens semi-structurés avec des adolescents recevant des soins psychiatriques pour un refus scolaire anxieux et avec leurs parents. La collecte de données par échantillonnage raisonné s'est poursuivie jusqu'à ce que nous atteignions la suffisance théorique. L'analyse des données était thématique. **Résultats:** Cette étude comprenait 20 adolescents de 12 à 18 ans et 21 parents. Deux thèmes se sont dégagés de l'analyse: (1) les buts des soins psychiatriques avec deux sous-thèmes, « se transformer » et la résolution de problème;

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et (2) les leviers thérapeutiques identifiés comme étant efficaces avec deux sous-thèmes : le temps et l'espace, et les relations. **Conclusion:** Nos résultats montrent une divergence entre parents et adolescents dans leurs représentations des soins et surtout de leurs buts. Les implications thérapeutiques et pour la recherche des enjeux de retour à l'école dans le cadre de soins psychiatriques ainsi que la temporalité des soins sont discutées.

**Mots clés:** refus d'aller à l'école, adolescents, recherche qualitative, pédopsychiatrie, résultat déclaré par le patient

## Introduction

Adolescent school refusal is an increasingly frequent reason for families to seek psychiatric care, especially in France. Around 90% of the adolescents refusing to go to school may have a psychiatric diagnosis (Ek & Erickson, 2013), most often a type of anxiety disorder described as *anxiety-based school refusal*. This diagnosis is studied worldwide and is most often associated with other anxiety, phobic, or depressive disorders (Kearney & Albano, 2004; Witts & Houlihan, 2007). This growing problem intersects with both education and public health policies because of its potentially serious academic, social, and psychiatric consequences (McCune & Hynes, 2005).

From a treatment perspective, care can often be complex and long, especially in situations in which adolescents have disconnected completely from school. Several trials have validated the use of some types of individual therapy, in particular, variants of cognitive-behavioral therapy (CBT) (Maric, Heyne, MacKinnon, van Widenfelt & Westenberg, 2013) and dialectical behavior therapy (Chu, Rizvi, Zende-gui, & Bonavitacola, 2015). In practice, there are no established guidelines, and coordination between medical professionals, school staff, and family can be difficult.

At the same time, the role of patients in their medical care has evolved in recent years (Truog, 2012). Healthcare professionals must take patients' subjective health status into consideration. A new era of clinical research has emerged: patient-reported outcomes (PROs). PROs are assessments coming directly from the patients themselves reporting their thoughts, complaints, views or perspectives about their medical care, the benefits of treatment, and the healthcare outcomes important to them (Deshpande, Rajan, Sudeepthi, & Abdul Nazir, 2011). Similarly, proxy-reported outcomes are reports for the same purposes by someone other than the patient (parents, siblings, etc.). PROs and proxy-reported outcome can be explored using either quantitative (PRO measures) or qualitative methods (Donald, Gordon, & Acquadro, 2011). Pediatric PRO assessment is an even more recent field of research, and empirical evidence about quantitative instruments within this age-specific population is still scarce (Matza et al., 2013).

Qualitative methods seek to describe and understand in depth a complex phenomenon. They are a tool of choice for focusing on the views of patients, including adolescents (Revah-levy, Birmaher, Gasquet, & Falissard, 2007; Spodenkiewicz et al., 2013). Several qualitative studies

have already examined anxiety-based school refusal, in particular, the experience of parents (Brussard et al., 2015; Havik, Bru, & Ertesvåg, 2014) the viewpoint of school nurses (Torrens Armstrong, McCormack Brown, Brindley, Coreil, & McDermott, 2011), and the concerns of adolescents and mothers in this situation (Gregory & Purcell, 2014). The families included in the latter study complained that neither the school nor healthcare professionals listened to them adequately.

In adolescent psychiatry, the lived experience and the expectations of patients and their parents have a central role in treatment. To our knowledge, however, no study has yet explored how these adolescents and their parents experience the psychiatric care provided to them. This study sought to explore this experience with a qualitative method and to compare the perspectives of the adolescents and their parents. This work is an initial step in the evaluation of PROs and their role in improving the quality of care (Deshpande et al., 2011).

## Methods

### Setting

This exploratory multicenter study took place at three adolescent psychiatry departments: at the Hospital Center of Argenteuil, at Salvator Hospital in Marseille, and at the hospital Center of Rouen. These three centers offer similar care for the management of anxiety-based school refusal in adolescents. Each center has an outpatient unit, a day-hospital and an inpatient unit. Hospital staffs were quite similar, composed of psychiatrists, psychologists, occupational therapists, nurses, and social workers. Individual interventions and therapy groups were available to adolescents within the units. A clinical coordinator was selected in each department. The council for the evaluation of ethics in health research of the University of Paris-Descartes approved the protocol. All patients and their parents provided written consent before inclusion in the study.

### Sampling and Participants

Sampling was purposive (Patton, 2001), that is, selective and deliberate. The researchers explained the study design in detail to the clinical coordinator at each center. The clinicians then identified potential participants — adolescents and parents — whom they considered likely to provide the most information.

**Table 1. Interview guide**

	Area of experience	Potential questions
1.	Disease history, onset of the disease	How long have you had this disorder? How was it discovered?
2.	Help-seeking process	Can you tell me about how and you started receiving psychiatric care?
3.	The beginning of treatment	Can you tell me about your first meeting with your psychiatrist and with the other staff?
4.	Treatment decisions	How did you understand and experience the treatment plan?
5.	Treatment options	What treatment options were suggested to you?
6.	Perceived effectiveness of each type of care received	In this treatment, what helped you, what was effective? In this treatment, what didn't help you, what was harmful?

The inclusion criteria were: adolescents, boys and girls, aged 12 to 18 years, speaking fluent French, with anxiety-based school refusal resulting in complete school disconnection that led to treatment, begun at least six months earlier, and clinically determined to be well enough to participate in a research interview.

Anxiety-based school refusal is not recognized as an independent diagnostic category in the current classifications of psychiatric diagnoses (Kearney, 2008). Adolescents included in the study had to meet four criteria, based on the classification proposed by Berg (2002): (1) refusal to attend school (to operationalize this first criterion, adolescents were included if they had not attended school at all for at least one month before starting treatment); (2) presence of a DSM-5 anxiety disorder (except obsessive-compulsive or post-traumatic stress disorders) with emotional upset at the prospect of attending school; (3) absence of a DSM-5 conduct disorder; and, (4) parental knowledge of the adolescent's whereabouts during the period of non-attendance. At each center, the clinical coordinator evaluated candidates during a clinical interview to assess the diagnosis and verify these criteria.

The clinicians first mentioned the study to potential participants and gave them an information sheet about it. If they expressed interest, a preliminary meeting took place, in which one of the researchers spoke with the teen and his or her parents to describe the study to them and obtain their written consent. This preliminary interview also provided the occasion to collect social and demographic data.

### Data collection

Data came from semi-structured interviews that used an *open-ended approach* (Britten, 2013). The interviewers used an interactive conversational style and a list of areas of experience to explore for both adolescents and parents (table 1). Interviewers also sought to enter the interviewees' psychological and social world and to remain open and attentive to any unknown issues that might appear. The

participants were considered to be the experts on their own experience, and the interviews were conducted in a way that offered them the opportunity to recount it.

The objective of the interview was to obtain an in-depth description by participants of their experience of the treatment they received. We were not seeking to assess the effectiveness of any given treatment or intervention, which is not something that qualitative research can do; rather it makes it possible to examine closely how patients and their families experience their treatment.

A researcher interviewed each adolescent and then one or both parents. There were thus two interviews for each family, both by the same researcher. Each interview lasted from 60 to 90 minutes. They were conducted by two experienced researchers (JS, an adolescent psychiatrist, and MO, a clinical psychologist), from September 2014 through March 2015. The interviews, which have been anonymized, were recorded and transcribed word-for-word, including the participants' expressive nuances. The transcript thus obtained was then analyzed.

Our sample size was determined according to the principle of theoretical sufficiency (Dey, 1999). That is, data collection and analysis were completed when the researchers determined that the themes obtained offered a sufficient explanatory framework for the data collected. Two further dyads have been included with no new themes emerging from analysis, to ensure theoretical sufficiency.

### Analysis

We used thematic analysis to explore the data (Braun, Clarke, & Terry, 2014). This method enables the identification, analysis, and reporting of the themes within the data. Our thematic analysis was data-driven and used an inductive approach: a process of coding the data without any reference to theoretical notions or researcher's preconceptions

Table 2 summarizes the different stages of our thematic analysis. This process is dynamic and iterative, with each

**Table 2. Process of inductive thematic analysis**

	Activities	Rationale
Stage 1	Repeatedly read each transcript, as a whole	Obtain a global picture of the interview and become familiar with the interviewee's verbal style and vocabulary. Each new reading of the transcript might also provide new perspectives.
Stage 2	Code the transcript by making notes corresponding to the fundamental units of meanings.	Make descriptive notes using the participant's own words. Pay particular attention to linguistic details, such as the use of metaphor.
Stage 3	Make conceptual notes through processes of condensation, abstraction, and comparison of the initial notes.	Categorize initial notes and reach a higher level of abstraction.
Stage 4	Identify initial themes. Provide text quotes that illustrate the main ideas of each theme.	Themes are labels that summarize the essence of a number of related conceptual notes. They are used to capture the experience of the phenomenon under study.
Stage 5	Identify recurrent themes across transcripts and produce a coherent ordered table of the themes and sub-themes.	Move from the particular to the shared across multiple experiences. Recurrent themes reflect a shared understanding of the phenomena among all participants.  During this more analytic stage, researchers try to make sense of the associations between the themes found.

new transcript leading to the collection of additional data and to their subsequent analysis. The objective was to identify the similarities and the differences between the accounts of each participant. The researchers were thus led to discern the recurrent patterns but also to integrate the new issues that emerged from the analysis.

Three researchers (JS, MAP, and MO) independently performed this analysis with Nvivo 11 software. Moreover, results were regularly debated during research group meetings. In cases of disagreements, the discussion continued until a consensus was reached.

## Results

The study included 20 adolescents – nine girls and 11 boys – and 21 parents – 17 mothers and four fathers – for a total of 41 participants. Table 3 summarizes their characteristics. All the adolescents recruited agreed to participate. We conducted 40 separate interviews, with one pair of parents interviewed together. In all the other cases, the one parent present explained that organizational problems prevented the other (most often the father) from attending.

The teens' ages ranged from 13 to 18 years and averaged 15.5 years. This was a clinical population with diverse anxiety disorders: separation anxiety disorder (N=7), generalized anxiety disorder (N=6), social phobia disorders (N=6), and panic disorders (N=2). Half also had a comorbid depressive disorder (N=10). The duration of psychiatric care ranged from 14 to 79 months, with a mean duration

of 38.1 months. All the adolescents interviewed had been hospitalized either full-time or in the day hospital unit of their hospital's psychiatric department. Seventeen had undergone individual psychotherapy: cognitive-behavioral therapy (N=10), psychodynamic therapy (N=7), and interpersonal therapy (N=3). Five families had participated in family therapy sessions. Sixteen young people had received pharmacological treatment: selective serotonin reuptake inhibitors (N=13) or atypical antipsychotics (N=3).

GAD: generalized anxiety disorder; DH: day hospital; IP: individualized psychotherapy; SSRI: selective serotonin reuptake inhibitor; SAD: separation anxiety disorder; FT: family therapy; AAP: atypical antipsychotics; SAD: separation anxiety disorder; FTF: full-time hospitalization

Regardless of the treatment these adolescents received, the analysis of the interviews enabled us to identify two common themes: (1) the goals of psychiatric care, with two sub-themes "*Self-transformation*" and *Problem-solving* and (2) the therapeutic levers identified as effective with two sub-themes, *time and space* and *relationships*. The results are presented below and relevant quotations from the transcripts in Table 4.

### 1. The goals of psychiatric care

Adolescents and parents described the goals of psychiatric care related to their understanding of their disorder. Care was judged valuable and meaningful if it dealt with the issues identified by the parents and the adolescents.

**Table 3. Participants' characteristics**

N	Sex	Age	Duration of care (in months)	Anxiety disorders	Comorbidities	Treatments received	Parent interviewed
P1	F	15	40	GAD	Major depression	DH, IP, SSRI	mother
P2	F	18	79	SAD	Major depression	DH, IP, FT, SSRI	mother
P3	M	16	26	GAD		DH, IP, AAP	mother
P4	M	17	55	Social phobia	Persistent depressive disorder	DH, IP, SSRI	mother
P5	F	14	14	SAD		DH, IP, FT, SSRI	father
P6	M	17	47	SAD	Major depression	DH, IP, SSRI	mother
P7	M	18	50	Social phobia		DH, IP, AAP	mother and father
P8	F	14	22	Social phobia	Emetophobia	DH, SSRI, hypnosis therapy	mother
P9	M	16	37	SAD	Persistent depressive disorder	DH, FTH, SSRI	mother
P10	M	14	33	social phobia	Dyslexia-dysorthographia	DH, hypnotic medication	mother
P11	M	18	48	GAD	Major depression	DH, IP, SSRI, hypnotic medication	mother
P12	M	14	24	GAD	Major depression	DH, IP, SSRI	mother
P13	M	13	15	SAD		FTH, IP	father
P14	F	16	63	Panic disorders with agoraphobia	Persistent depressive disorder	DH, IP, AAP	mother
P15	M	14	34	SAD	Persistent depressive disorder	DH, IP, FT, SSRI	mother
P16	F	14	26	GAD	Major depression	FTH, IP, SSRI	mother
P17	F	18	36	GAD		DH, SSRI	mother
P18	M	15	21	Panic disorders with agoraphobia		DH, IP, SSRI	mother
P19	F	13	49	SAD, social phobia		DH, IP	mother
P20	F	17	43	social phobia	Major depression	FTH, IP, FT, SSRI	father

GAD: generalized anxiety disorder; DH: day hospital; IP: individualized psychotherapy; SSRI: selective serotonin reuptake inhibitor; SAD: separation anxiety disorder; FT: family therapy; AAP: atypical antipsychotics; SAD: separation anxiety disorder; FTF: full-time hospitalization

### 1.1 Self-transformation

Most of the adolescents considered that they themselves were the source of their problems. They mentioned internal malaise, suffering, or distress, and they used terms of psychiatric semiology to describe it: depression, anxiety, or anguish. Some also stressed their lack of self-esteem and self-confidence (Q1). This internal distress was experienced as invisible from outside. Adolescents reported that their parents, their peers, and sometimes even the healthcare professionals denied their suffering, did not believe them (Q2). School was perceived not as the cause of the disorders but as the place where their pain was expressed (Q3).

Parents also considered their child's disorder as internal distress. Nonetheless most parents identified it only afterwards, based sometimes on the psychiatrist's discourse (Q4 and Q5). Adolescents therefore considered that what they needed was to change and develop. Some adolescents described this change as a disappearance – diminution or absence of psychiatric symptoms – and/or a gain – more self-confidence, autonomy, and maturity, better self-knowledge (Q6), or even self-transformation (Q7).

Parents recognized this personal change and considered it beneficial. They welcomed it with surprise, without really

relating it to the psychiatric care process, but rather to the child's own development (Q8).

While most of the teens recognized that they had changed during the period of care, they remained uncertain about the process that led to this change. Their discourse about the pharmacological treatment illustrated this perplexity. How could they be sure that the drug was really responsible for the change (Q9)?

Other adolescents mentioned their difficulty in perceiving changes by themselves. They needed these to be identified and validated from the exterior, to be told that they were changing (Q10).

### 1.2. Problem solving

For parents, care essentially involved a problem-solving model. They identified problems for which psychiatric care was supposed to find solutions (Q11).

*Problems with school, solution by the school.* Parents' principal worries concerned school and the academic consequences of their child's situation. Parents were especially afraid that their children would fail a year and have to repeat it. Many also reported problems within schools and the educational system: too much pressure on students, harassment, teachers who are too strict; or with the professional staff: failure to understand individual situations, lack of flexibility of the school structure. All of these problems together motivated parents to seek care for their child (Q12).

Adolescents also mentioned these school problems, but always secondarily. They were nonetheless well aware that the issue for their parents was their education (Q13).

Parents thus considered solutions that directly affected school problems to be relevant and useful: adapting and maintaining their schooling, setting up distance courses, including class time in the day hospital schedule (Q14). Parents and, to a lesser degree, the adolescents described not having to repeat the year or not giving up as criteria to assess the efficacy of the proposed solutions (Q15). All parents associated the effectiveness of treatment with support for return to school (Q16). For many parents, as well as some adolescents, return to school and recovery were essentially the same (Q17).

*Problem of social life, solution by socializing within the institution.* The second problem underlined by parents was the child's lack of a social life. Parents were particularly worried about their child's isolation and difficulty in fitting into a peer group (Q18). Adolescents also recognized their difficulties in socializing and in interacting with others (Q19).

Parents thus considered that in-patient or day care provided a solution by enabling their children to socialize with others. They described the hospital as a place for a social life adapted to their child (Q20). Day hospitalization provided

them with the advantage of giving back to the family in general and the child in particular a normal life rhythm (Q21). The adolescents also mentioned the need for a social life and social skills, but underlined especially the importance of fitting into a peer group (Q22).

## 2. Therapeutic levers identified as effective

### 2.1. Time and space

*Taking time or wasting time.* The adolescents considered that the time necessary for care to be effective had to be taken. First, they thought that professionals had to take the time to name and define their distress. Next, it would take time for the adolescent to "encounter" the care and the professionals providing it, that is, to adhere to the treatment activities proposed, and trust the staff. Finally, it took time to think about oneself and be able to develop (Q23, Q24).

Some parents were also very satisfied about the time given to their child to adhere progressively to treatment and to get to know the healthcare team (Q25).

Nonetheless, parents had difficulty accepting that treatment couldn't be effective faster, that they hadn't found the right professional, the right solution, or the right treatment from the beginning. Parents then mentioned that time was being wasted (Q26).

Teens, however, replaced this concept of wasting time with that of experimentation and trial; they considered that all the stages of care, even those that were not effective, had been useful in one way or another (Q27).

*Need for a space.* Parents emphasized the need and importance of the space of care. They experienced the treatment in an inpatient unit or a day-hospital as the end of wandering (Q28). Parents considered the environment where treatment occurred as a therapeutic lever (Q29). The space of care was very often compared with school and described as more benevolent, friendlier, more welcoming, and more open to the outside world (Q30).

Some adolescents described a sense of belonging within the space of care (Q31). Nevertheless, many of them valued the people they met within the psychiatric department more than the place itself (Q32).

### 2.2. Relationships

Participants considered relationships to be an essential therapeutic lever. They underlined the importance of being able to speak and be heard as well as the need to establish a trusting relation with hospital staff (Q33). Of the range of relationships related to this psychiatric care, adolescents and their parents had anticipated some, while others were considered unexpected and thus experienced as still more effective.

*Expected relationships: with healthcare staff, family, and peers.* Adolescents and parents insisted on the personal and

**Table 4. Quotations**

<b>Theme 1: The goals of psychiatric care</b>	
<i>1.1 self-transformation</i>	
Q1	P4: I was timid and withdrawn (...) I didn't like myself, I just stayed in my room being depressed.
Q2	P8: Even when I felt bad, everyone thought I was well.
Q3	P2 Just as I was about to leave, I had trouble breathing, I had a knot in my stomach; it just came over me, it made me anxious, just thinking about it, I was stuck. In fact, it was me; I was stuck, I couldn't even get out the door, I didn't want to.
Q4	Mother of P7: He's a very anxious child. Doctor C. told us that she has rarely seen such anxiety in a child. It's his temperament; we understand that now.
Q5	Mother of P12: I really didn't imagine that he was deeply depressed, in fact, and in the end, he was deeply depressed. Truly he was becoming depressed, the poor kid, and at the beginning, I didn't believe him really, no. At the beginning, I didn't believe it, and my husband didn't either.
Q6	P18: It is a personal development; I think I became more mature.
Q7	P9: It transformed me (...) the day hospital helped me to make myself into a person. And today, all those things that I received there for two years made me the person that I am today, right now.
Q8	Mother of P17: She's become a little more responsible, she's left that child part behind, she's grown up.
Q9	P 16 After, the antidepressant, it would be a little harder to attribute the effects, to the extent that there was a change, but I can't really say how much the antidepressant was responsible for it.
Q10	P11: I was changing, but it wasn't really clear in my head (...) In fact, there was a sort of fog, and the fog made it ... I wasn't sure about it, and when it was gone, I saw what they were telling me, I understood that it was better.
<i>1.2 Problem solving</i>	
Q11	Mother of P9: I came here. Why? Because I knew that I was going to find people to talk to who were not necessarily going to give me the solution, but would help me find a solution. Either they would give it to me, or I would find it. Problems with school, solution by the school
Q12	Mother of P8: So that she wouldn't get too far behind, I found a hospital that could give her courses in French and math and at the same time, get her to leave the house. And then she was in a world that understood her.
Q13	P19 (on the subject of her father and the suggestion for full-time hospitalization): To start with, he doesn't really like shrinks. I don't know exactly why. He wants me to have a regular education, for me to go to middle school. So he finally agreed, but it was a little harder.
Q14	Mother of P8: (What helped you the most?) When they set up the distance classes for her.
Q15	Mother of P8: But when she came here to do math and French, I knew that it wasn't at a very high level (...) But it kept her from losing touch with schoolwork and that ... that really helped.
Q16	Father of P5: Today, she turned a corner. She agreed to go back to a normal school program, on condition that it's not at her original school.
Q17	Mother of P9: When he finished all his internships and had his diploma, I knew it was over. Problem of social life, solution by socializing within the institution
Q18	Mother of P12: And then the contact with the others, quite simply, it was too hard for him to be in contact with the others, fear, I don't know, a fear of people.
Q19	P11: Conversation with the people around me was very complicated; I didn't dare say anything to people.»
Q20	Mother of P4: So here, there was socializing with activities, horseback riding, sports, and then he was very happy to make friends, to win at foosball.
Q21	Mother of P9: It was impossible for him to stay home, all alone (...) Since I work, I couldn't just stay home when I wanted to. I couldn't take time off, or sick leave. I had to do something. So the doctor suggested the day hospital, where he would go in the morning and he would come home in the evening.
Q22	P1: I found my two best friends, I met them here.
continued	

<b>Table 4. Quotations</b>	
<b>Theme 2: Therapeutic levers identified as effective</b>	
<b>2.1 Time and space</b>	
<i>Taking time or wasting time</i>	
Q23	P2 It's me, and also time. Time helps, being able to think about myself.
Q24	P16 I've grown up some, and I feel ready. I think I needed some time.
Q25	Mother of P3: It was long... really, little by little... It took a long time, all of this .... it was five minutes, ten minutes, 15. And little by little, he wasn't aware of the time anymore and after it was ok. We spent the time here, and he accepted it afterwards.
Q26	Father of P5: What could have stopped this? I think it's that we waited too long for the antidepressant. We wasted time, I think.
Q27	P2: There were a lot of failures. But, I don't think you can say that it didn't help me, either. Because it's from these mistakes that we learned things and exactly how we were able to find other solutions.
<i>A need for a space</i>	
Q28	Mother of P1: And finally the day-hospital. We felt so relieved. I mean, finally only one place where they could take care of everything. XXX [name of the daughter] just had to make the effort to come here in the morning.
Q29	Mother of P3: Look at this place, the park, the trees, how can you not feel better here?
Q30	Father of P20: School was like cold and not flexible, here it's different, it's more...more... I don't know but here they adapt, they really try to welcome you the best they can, to be nice and friendly.
Q31	P3: I was feeling good here, I was feeling like I belong.
Q32	P5: After it's not necessarily the place itself, being in a hospital that helps. It can be the people, if you run into good people.
<b>2.2 Relationships</b>	
Q33	Mother of P3: I think that they feel that the staff is there to listen to them, and if you want to talk, you talk. That's certainly very positive.
<i>Expected relationships: with healthcare staff, family, and peers</i>	
Q32	P5: After it's not necessarily the place itself, being in a hospital that helps. It can be the people, if you run into good people.
Q34	P1: With one nurse, I had a good relationship, we liked each other a lot; she gave me advice. When she left for somewhere else, that hurt me a lot. I had succeeded in having a very good relationship with her.
Q35	P10 (what do you think of your relationship with your psychiatrist?): It was a professional relationship. We talk, we assessed the month, she gave me tools and helped me understand. I think it was good.
Q36	P9: Frankly, it's thanks to my mother that I'm here now; she's really the one who supported me and got me here.
Q37	P20: During my hospitalization, they finally understood that they shouldn't protect me all the time, that they needed to have a little more confidence in me .... The hospitalization helped them too, in fact.
Q38	P4 (Do you sometimes talk about your problems?) Yes, sometimes. To reassure myself. To talk, yes. I think that also is sort of the aim of this place. There are nurses, but there are also teens. I think it also helps to talk to people your own age.
Q39	Mother of P5: She said she was shocked sometimes, by the behavior of some of the young people here. The other day, she was faced with someone who pulled out a knife, saying he wanted to kill himself. She talks to us about it often.
<i>Unexpected relationships</i>	
Q40	P6: I had a taxi driver who I got along with really well. He was more a friend for me, than anything else, more than a taxi driver, finally (...) I talked to him about a lot of things, he introduced me to a lot of movies...
Q41	P8 The teachers here, they give us confidence, they explain things clearly. They follow us, they really don't want to leave us in something we don't know. And that helps a lot. We feel that it pleases them, that they want us to succeed, so that does a lot for us.
Q42	Mother of P4: And little by little there's someone great, it's the math teacher (...) she does everything for the ... like a horse that you've tamed.

emotional aspects of their relationships with staff. Adolescents looked for the person behind the function (Q32) and were sensitive to the quality of staff investment and commitment to them (Q34). On the contrary, parents and adolescents designated the psychiatrist as the professional in the healthcare system. This relationship was less emotional, more distant, more focused on the adolescent's therapeutic management (Q35).

For the adolescents and their parents, intrafamily relationships and the adolescent-parent relationship provided support, in particular at the onset of care (Q36). Teens also mentioned that modifications of their interactions with their parents — especially around questions of autonomy — had been helpful in their care (Q37).

Adolescents generally experienced their relationships with peers as positive and helpful. They were able to help each



other, reassure each other, and talk about their problems with people their own age (Q38). Parents recognized these positive aspects but also worried about their child being in contact with “very sick” or “special-needs” teens (Q39).

*Unexpected relationships.* Besides these expected relationships linked to their psychiatric care, adolescents recognized as still more effective and helpful some unexpected relationships that they were able to establish in the course of care.

In particular, these were unexpected meetings: the taxi driver bringing them to the hospital, an intern, or an art therapist. These relationships were experienced as more therapeutic than the others (Q40). Sometimes, it was an activity offered to the adolescent and experienced as unexpected (African dance, gardening) that served this function of therapeutic lever.

In this context of anxiety-based school refusal, adolescents reported unexpected experiences with teachers in the hospital. These teachers were described as kind, patient, and altruistic. Adolescents thus had the chance to have a relationship they experienced as different and healing (Q41). Parents shared this position and considered the relationship between their child and some teachers as decisive (Q42).

## Discussion

We first observed a divergence between the representations of the goals of care between adolescents and parents. While parents focused on the external goals, adolescents focused their care more on internal issues. The parents’ focus matches those found in the literature: studies assessing the efficacy of therapy, especially CBT, in situations of anxiety-based school refusal consider return to school, as quickly as possible, as the primary outcome and internalized behaviors or depressive features as secondary (Maric et al., 2013). Moreover, although CBT has shown some effectiveness in promoting school attendance and reducing emotional symptoms in children and adolescents with anxiety-based school refusal (King et al., 2001), a study focusing on adolescents alone reports a poorer response (Bernstein et al., 2000). As in our sample, adolescents may present more severe forms of anxiety-based school refusal and more frequent association with depressive disorders than younger children do (Heyne, Sauter, Van Widenfelt, Vermeiren, & Westenberg, 2011).

For many parents, return to school and recovery were essentially the same. We think that there is a risk of a cessation of care because parents would no longer consider care as necessary whereas the internal goals of care of the adolescents would not yet be achieved. This could lead to the development of an untreated internalized disorder. Authors of a recent review noted the need for long-term follow-up studies to determine whether school attendance among adolescents with anxiety school refusal ultimately

leads to reduced anxiety (Maynard et al., 2015). The study by McCune & Hynes (2005) of the outcome of adolescents with anxiety-based school refusal reported that 30% had a psychiatric disorder ten years later.

Moreover, time appears in our results as an essential therapeutic lever for the teens. Here again, we identify divergences in the representations of parents and adolescents. Parents want an effective treatment as rapidly as possible, while adolescents claim the need of a treatment period sufficiently long to allow them to change and develop.

This result is consistent with the interrelation between adolescents’ development of autonomy and the process of care. Indeed, our results – “self-transformation” and *taking time* – suggest a process of becoming within the care and especially how time is needed to enable such a process. In that respect, some authors argue that adolescent-focused CBT for anxiety-based school refusal must take into account the developmental aspect of the adolescence period (Heyne et al., 2011). To our knowledge, however, the question of the length of care in adolescent psychiatry has never been studied as a therapeutic lever but only as a variable associated with the establishment of a good therapeutic alliance (Topor & Denhov, 2012). Further research should explore this question in depth.

Although the adolescents in our results valued the time and relationships more, the space of care appeared to be a shared therapeutic lever between parents and adolescents. The qualitative literature has already described the importance of the *therapeutic milieu* in adolescent mental health care (Geanellos, 2000) but the question of the therapeutic value of the place where care occurs has never been studied in adolescent psychiatry. The relational dimension of treatment is the second therapeutic lever described by adolescents and parents. The importance of relationships in adolescent psychiatry, in particular with hospital staff, is clear in the literature (Karver, Handelsman, Fields, & Bickman, 2006; Shirk & Karver, 2003), especially linked to the concept of therapeutic alliance. The studies suggest that a good alliance is necessary, as much with parents as with adolescents, although these two relationships predict different outcomes (Hawley & Weisz, 2005; Kazdin, Marciano, & Whitley, 2005).

Our study reports an original result: the therapeutic value of experiencing unexpected care-linked relationships. Time, space, and relationships — the therapeutic levers found in our results — are in fact strongly intertwined. That is, we can argue that treatment must last long enough, in a place dedicated to care, to allow these youth to become involved in their care and to reflect on the personal changes they need, but also to offer them the possibility of multiple human encounters, some of which — expected or unexpected — will turn out to be determinant in their development. Our results suggest therefore two outcomes of care that might seem antagonistic: a rapid return to school for the parents,

and a sufficiently long time within care to enable a self-transformation for the adolescents. These two outcomes are of equal importance and psychiatric treatment should strive to combine and coordinate them.

These results take place in a current discussion in the literature about the time and space of care in this situation, as many authors warn against the risk of chronicity without a quick return to school (Kearney, 2008). Some authors also consider that a timely and well-prepared return to school enables adolescents to develop within his or her social and school world, a more naturalistic setting than a psychiatric day hospital or an inpatient unit, while continuing to receive care in an outpatient unit (Maynard et al., 2015).

Our results provide another point of view and show that, for adolescents with severe or persistent anxiety-based school refusal, self-transformation and another relationship with school is possible within psychiatric care and in a psychiatric space. In France, this is the case for instance in psychiatric units named “care study” providing day-hospital or inpatient treatment in which the adolescent can continue his or her academic education (Chandelier, Atger, & Peyre, 2014). Thus, our results invite us to question the space of care, in other words the setting to be proposed in case of an anxiety-based school refusal, especially when severe and persistent. Further research about this specific topic appears necessary.

Moreover, further PROs among adolescents with anxiety-based school refusal should integrate the assessment of both external and internal goals of care and the duration of care and of expected and unexpected care-linked relationships.

## Limitations

This is the first qualitative study to look at the experience of psychiatric care for adolescents with anxiety-based school refusal.

Nonetheless, some limitations must be taken into consideration. First, it took place in France, and caution is required in transposing our results to other places because psychiatric care depends strongly on the organization of the medical system as well as on the country's economy. Second, the population of adolescents was recruited in specialized departments of adolescent psychiatry. Our results therefore apply to this population receiving this kind of care in these types of settings, but they cannot take into account other contexts of care for the same disorder, especially outpatient management or school-based programs (Garmy, Berg, & Clausson, 2015). Third, this study's objective was to understand the global experience of psychiatric care and not to classify the experience of specific interventions. Future qualitative research should be able to explore in depth the experience of particular therapies in this population. No study has yet explored the points of view of psychiatrists and other mental health professionals about the care of

these adolescents. Such a study might make it possible to clarify the views and perspectives of professionals about goals of care and therapeutic levers. Finally, our study was able to identify significant concepts regarding the experience of care in this situation, but further studies are needed to enable an in-depth description of them, to examine them in different situations, and to explore their relations with other concepts already described in the literature (Morse, 2012).

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