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A qualitative study of adolescents with medically unexplained symptoms and their parents

MOULIN Virginie

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UNIVERSITE DE LAUSANNE - FACULTE DE BIOLOGIE ET DE MEDECINE

Groupe de Recherche sur la Santé des Adolescents (GRSA)
Institut Universitaire de Médecine Sociale et Préventive (IUMSP)

A qualitative study of adolescents with medically unexplained symptoms and their parents

THESE

préparée sous la direction du Professeur associé Joan-Carles Suris
(avec la co-direction du Docteur Pierre-Yves Rodondi et la collaboration
de Christina Akre)

et présentée à la Faculté de biologie et de médecine de
l'Université de Lausanne pour l'obtention du grade de

DOCTEUR EN MEDECINE

par

Virginie MOULIN

Médecin diplômée de la Confédération Suisse
Originaire de Mosnang (SG)

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A qualitative study of adolescents with medically unexplained symptoms and their parents

Lausanne, le 12 janvier 2016

pour Le Doyen
de la Faculté de Biologie et de Médecine

Monsieur le Professeur John Prior
Vice-Directeur de l'Ecole doctorale

Résumé en Français :

Étude qualitative sur les symptômes médicalement inexpliqués chez les adolescents

Il est fréquent en médecine de premier recours de rencontrer des adolescents exprimant des symptômes somatiques pour lesquels aucune des investigations entreprises n'a permis de rendre compte d'une pathologie organique. De tels symptômes sont retrouvés dans la littérature sous la terminologie de symptômes médicalement inexpliqués (MUS) ou des troubles fonctionnels.

Bien que la prévalence des adolescents souffrant de MUS est fréquente, les médecins éprouvent encore beaucoup de difficultés à prendre en charge et communiquer avec ces patients, principalement en raison d'une incompréhension de leurs besoins et préoccupations tant dans leur vie quotidienne que lors d'une consultation au cabinet.

Le but de notre étude est de comprendre les expériences et vécus des adolescents avec des MUS ainsi que de leurs parents afin d'aider le praticien dans la compréhension de son patient dans sa globalité et ainsi d'améliorer sa prise en charge.

Dans le premier article présenté, nous nous sommes intéressés à la vie quotidienne de ces adolescents en étudiant leurs relations avec leur famille et leur entourage ainsi que les répercussions sur leurs parcours scolaire et leurs activités extrascolaires. Dans le second article nous nous sommes penchés sur les relations qu'entretiennent ces adolescents et leurs parents avec le système de santé. Nous avons collecté des données qualitatives en moyennant des groupes focus incluant 16 adolescents atteints de troubles fonctionnels et leurs parents. L'analyse a permis de faire émerger les difficultés que ces jeunes et leurs familles vivent au quotidien et comment ils sont confrontés à la solitude dû principalement à l'incompréhension sociale. Les résultats mettent aussi en évidence l'insatisfaction de ces jeunes et de leurs parents par rapport à la prise en charge médical, notamment en raison d'un manque de communication.

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A qualitative study of adolescents with medically unexplained symptoms and their parents. Part 1: Experiences and impact on daily life

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ABSTRACT

Medically unexplained symptoms (MUS) are common among adolescents and are frequently encountered in primary care. Our aim was to explore how these adolescents and their parents experience the condition and its impact on their daily lives and to provide recommendations for health professionals. Using a qualitative approach, six focus groups and two individual interviews were conducted. These involved a total of ten adolescents with different types of MUS and sixteen parents. The respondents were recruited in a university hospital in Switzerland. A thematic analysis was conducted according to the Grounded Theory. The analysis of the data highlighted four core themes: disbelief, being different, concealing symptoms, and priority to adolescent's health. Transcending these themes was a core issue regarding the discrepancy between the strategies that adolescents and their parents use to cope with the symptoms. Health professionals should be made aware of the emotional needs of these patients and their families.

Introduction

Headache, stomach-aches, dizziness and being overtired are common complaints in adolescence (Griffin & Christie, 2008). These physical, subjective symptoms can have an identifiable organic basis, but sometimes cannot be explained by any conventionally defined disease. These medically unexplained symptoms (MUS) are common and important problems in primary care. Previous surveys highlighted prevalence rates for adolescents that range from 3% for stomach-aches to 46% for headaches (Bohman et al., 2012; Dhossche, Ferdinand, van der Ende, & Verhulst, 2001; Janssens, Oldehinkel, & Rosmalen, 2009; Janssens et al., 2011; Steinhausen & Winkler Metzke, 2007). However, MUS constitute a broad and heterogeneous spectrum of bodily complaints where severity, duration of symptoms and comorbidities are present in different degrees

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(Smith & Dwamena, 2007). Many patients who are seen in primary care consult for one single MUS (T. C. Olde Hartman et al., 2013), most of which are benign, transient self-limiting conditions that have no significant impact on functioning or wellbeing and require no further medical attention after one or two consultations (Fink, Rosendal, & Olesen, 2005; Mayou, 1991; Swanson, Hamilton, & Feldman, 2010). Even if MUS do not indicate psychiatric disorders and many patients do not have one (Nettleton, 2006), when symptoms become marked, persistent, and remain unexplained after pediatric examination, they can cause considerable distress and impairment (Garralda, 2011) and psychiatric comorbidities often appear (T. C. Olde Hartman et al., 2013). Moreover, MUS can also have multiple presentations (MMUS). In these cases comorbidities occur more commonly, predominantly anxiety and depression (T. C. Olde Hartman et al., 2013). Studies have shown that MUS may be linked to school absenteeism (Lester, Stein, & Bursch, 2003), anxiety and depression (Janssens, Rosmalen, Ormel, Van Oort, & Oldehinkel, 2010) and family factors such as parents' psychological control, lack of parental warmth or affection (Rousseau et al., 2013), parental overprotection (Janssens, Klis, Kingma, Oldehinkel, & Rosmalen, 2014), rejection by parents (Lester et al., 2003) or conflict between parents (Bohman et al., 2012).

These patients are at high risk for unnecessary investigations, referrals and treatment with possibly iatrogenic effects (Hatcher & Arroll, 2008). Moreover, by that stage it is common for parents and children to believe that their doctor may have overlooked some medical problems and may lead them to experience repeated medical contacts with many specialists in the expectation of receiving medical treatment (Brown, 2004; Fink et al., 2005; Hatcher & Arroll, 2008).

Research conducted among adults revealed that the majority of MUS patients wish to be treated by their General Practitioner (GP). Their GPs also believe that these patients should be managed in primary care (Guthrie, 2008). However, they experience difficulty in dealing with MUS patients, because they find it difficult to decide when to end their investigations and also because they lack effective management strategies (Hansen, Rosendal, Fink, & Risor, 2013; Nunes, Ventura, Encarnacao, Pinto, & Santos, 2013; T. C. OldeHartman, Hassink-Franke, Lucassen, van Spaendonck, & van Weel, 2009; Reid, Whooley, Crayford, & Hotopf, 2001; Schaefert et al., 2013). Despite a strong clinical demand, no research has been conducted, to our knowledge, to understand the experiences and perceptions of adolescents with MUS and their parents. To fill this gap, this study attempts to explore what these patients and their parents undergo with the condition and its impact on their daily lives. By providing a more precise understanding of the impact of MUS on interactions within and outside of the family, this study underpins the development of recommendations to improve the care of these adolescents and to address the needs of their parents.

Methods

Procedure and recruitment

Participants were recruited within the pediatric department (adolescent health, orthopedics, gastroenterology, and rheumatology clinics) of a university hospital in Switzerland. Adolescents aged between 12 and 20 years, who spoke French fluently and who had been presenting with MUS for a minimum of six months, were eligible to participate with their parents. MUS were defined as any current somatic complaint that was reported by patients that had lasted more than six months and for which no definite medical diagnosis could be found after a physical examination and appropriate investigations. We consider as appropriate investigations exams that can exclude frequent pathologies that can mimic the symptoms. As MUS can only be diagnosed by excluding organic diseases (reference Classification and Diagnosis of Patients with Medically Unexplained Symptoms, JGIM 2007), we checked that investigations to exclude other diagnosis were made for each recruited patient. Each patient should have a large blood laboratory check and exams to exclude other diseases linked with the symptoms such as a colonoscopy for abdominal pain or an MRI for headaches. One investigator (VM) checked with each patient and the medical staff to ensure that the adolescent had undergone appropriate investigations before being classified as having MUS and included in the study. For inclusion in the study, it was also required that the adolescents and their parents live together.

Each clinic provided a list of patients and their postal addresses according to our inclusion criteria. We sent out a letter to each of them and one to their parents explaining the study aim and inviting them to contact us if interested in taking part in a focus group (FG). Letters were co-signed by the head of each clinic and of the research group. If they did not contact us spontaneously, they were contacted by telephone within a couple of weeks (Fig. 1).

Approval was obtained from the local Ethics Committee.

Focus groups

A qualitative approach appeared to be the most appropriate method in order to explore adolescents' and parents' experiences with MUS (Collingridge & Gantt, 2008; Rich & Ginsburg, 1999). We used a focus group (FG) method. This is particularly useful for exploring people's opinions, perceptions and experiences that can be difficult to uncover by other qualitative approaches (Duchesne and Haegel, 2004; Kitzinger, 1995). FGs offer the advantage of interaction among participants, as they question and explain themselves to each other. The FG method can also provide mutual support in expressing feelings (Duchesne and Haegel, 2004; Kitzinger, 1995; McClelland, Morgan, Leach, & Shelk, 1996; Morgan, 1996; Vermeire et al., 2002). In separate groups, adolescents and parents had the opportunity to freely express themselves about their experience.

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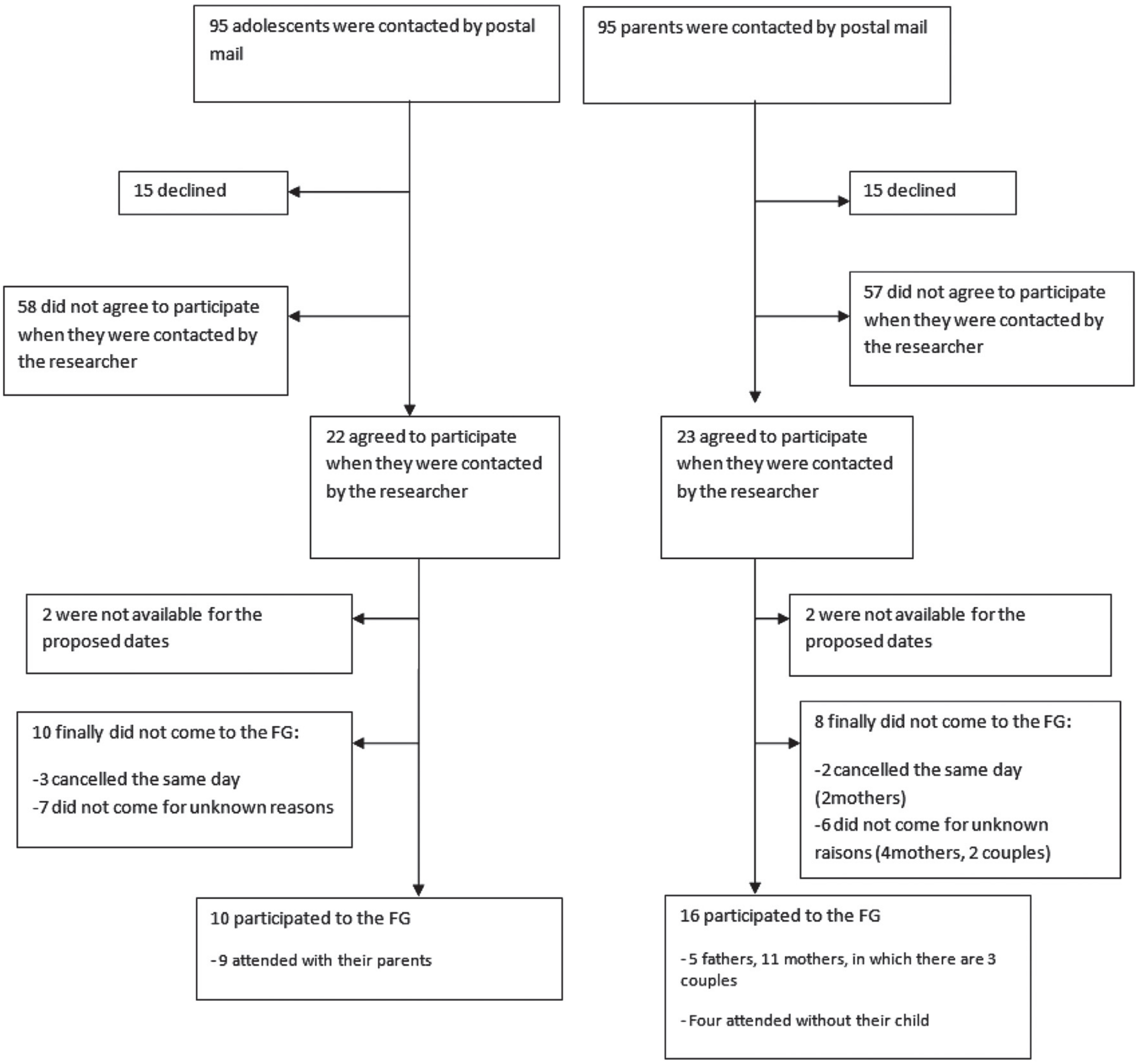

Fig. 1. Recruitment flowchart.

Because two participants (a mother and her daughter) were unable to attend their scheduled FG, they were interviewed individually. Although FGs and individual interviews are very different research methods and can reveal diverse data (Peterson-Sweeney, 2005), analysis showed quite similar data emerging from both methods in this case. Hence we decided to include these data in our analyses. For organizational simplicity, adolescents and parents participated between March and May 2014 in parallel groups at the same time. The adolescents' focus groups were stratified by age (12–15 and 16–20 years). As most adolescents arrived at the same time as their parents, the parents' FGs were formed according to the age of their children. The FGs were moderated by two researchers who were experienced in qualitative studies of adolescents. In each FG, one researcher served as discussion leader and the other took notes on the interactions. FGs lasted from 60 to 90 min and were audio-taped. At the beginning of each FG, participants signed a consent form and completed a short questionnaire to provide socio-demographic data in order to describe the sample. A consent form was also signed by a parent or legal representative of participants aged less than 16 years. All participants received a cinema gift card as an expression of appreciation for their participation.

The Functional Disability Inventory (FDI) was also completed by adolescents before the start of the FG to confirm that their condition had an impact on their daily life. This FDI has been developed and validated to assess activity limitations in children and adolescents who suffer from a variety of pediatric conditions (Claar & Walker, 2006; L. S. Walker & Greene, 1991).

We established an interview grid used during the FGs that included questions regarding daily life, school, activities, and relationships with family members and friends.

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Qualitative analysis

Recordings were transcribed verbatim anonymously and then deleted. The transcripts were read several times and coded according to a thematic analysis process, which implies an extraction of themes from the participants' discourse according to the Grounded Theory process (Collingridge & Gantt, 2008). The different codes were compared continuously during the analysis to detect similarities and differences. They were then grouped in broader categories and analyzed to determine elements that were relevant to the research questions. The analyses were undertaken by the first author, and systematically examined by the co-authors. The citations that appear in this paper were translated from French into English.

Results

Participants

Six FGs and two individual interviews were conducted. Three FGs were attended by a total of nine adolescents with MUS and the other three FG's were attended by a total of fifteen parents of adolescents with MUS. Each participant attended only one FG. Our sample included eleven mothers and five fathers, of which three were couples who attended the FG together. Seven girls and three boys participated. Nine of these children attended at the same time as their parents. The characteristics of participants and FGs are described in Tables 1 and 2.

Data analysis highlighted four main themes, which we labeled “disbelief”, “being different”, “hiding the symptoms”, and “adolescent's health first”.

Table 1
Participants' characteristics.

Parents (n = 16)	
Age (years)	
- mean	47.62
- range	38–55
Relationship to adolescent:	
- Mother	11
- Father	5
Marital status:	
- Married	11
- Separated/divorced	4
- Other (unspecified)	1
Recruitment clinic:	
- Adolescent health	9 (included two couples)
- Gastroenterology	5 (included one couple)
- Orthopedics	1
- Rheumatology	1
Adolescents (n = 10)	
Age (years)	
- mean	16.0
- range	14–19
Females/Males	7/3
Siblings	
0	2
1	3
2	1
3 or more	4
Education level:	
- Mandatory school	3
- High school	5
- Apprenticeship	2
Symptom's duration (years):	
- mean	3.75
- range	1–7
FDI score (/60):	
- mean	25.7
- range	14–38
Recruitment clinic:	10/95
- Adolescent health	6/26
- Gastroenterology	2/57
- Orthopedics	1/9
- Rheumatology	1/3

FDI: Functional Disability Inventory.

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Table 2
Focus groups' characteristics and list of symptoms.

FG[a]	Adolescents' age	Adolescents' gender	Symptoms	Parents' participation to the study
A1	18	F	Abdominal pain	Mother
A1	16	F	Polymyalgia	Mother and Father
A1	16	M	Knee pain	Father
A1	18	F	Dizziness, pelvic pain	Mother
A2	14	F	Joint pain	Mother
A2	15	M	Dizziness, headache	Mother and Father
A3	15	F	Foot pain	Father
A3	17	M	Abdominal pain, nausea	Mother and Father
A4	15	F	Back pain, joint pain	Mother
Adolescent who participated without their parents				
A1	19	F	Abdominal pain	None
Parents who participated without their child				
P2	15	F	Overtiredness, joint and muscle pain, dizziness	Mother
P2	15	F	Hyperphagia	Mother
P3	17	F	Abdominal pain, headache, overtiredness	Mother
P3	13	F	Abdominal pain	Mother

[a] A = adolescents' focus group, P = parents' focus group.

Disbelief

Both parents and adolescents reported that the absence of diagnosis represented a significant additional burden to the condition. This was partially explained as a perceived lack of understanding by family, friends and school.

All adolescents agreed that, when they first contracted their disease, their parents did not believe them. Reflecting their child's reports, most parents confessed that the absence of diagnosis brought up doubts regarding symptoms' truthfulness. On top of that, the constant change in their adolescent's attitude towards his or her complaints had also caused them to sometimes doubt the authenticity of the symptoms:

> “My daughter was not convincing at the beginning: she plays sports one day, the following day she stays in bed [because of the pain], two days after she plays sports again, she goes running … It's impossible!” (Father of a 15-year-old girl)

The authenticity of the symptoms was also questioned by siblings. Adolescents reported that their siblings accused them of feigning symptoms to receive attention from them, as well as to avoid household chores. This disbelief of siblings was also reported by parents, who added that siblings were sometimes jealous because of the feeling that the parents bestowed more benefits on the “MUS-child”:

> “I think that when my other children were jealous or didn't understand. […], it's because they had the feeling that we overlooked everything, that we accepted more coming from her” (Mother of a 16-year-old girl)

> “I couldn't do certain things that my parents asked me to do. And then, she [my sister] reacted by saying that I didn't do them [household chores] on purpose” (Female, 14 years old)

Both adolescents and parents also reported an important disbelief coming from classmates and friends who imagined that the symptoms were invented to skip classes and exams. However, they described better understanding among their close friends:

> “Regarding my friends, it's like you all said, there is no recognition, because … it's an internal pain. So it's invisible, and I'm not the kind of person who shows that I'm not doing well. So, apart from my best friend, nobody understands.” (Female, 16 years old).

In addition to suffering from friends' disbelief, adolescents and their parents struggled to prove to the school that the symptoms were indicative of a real health problem. It took a lot of energy and time for the parents to explain why their child missed school or should be exempt from physical education class:

> “Every three months, the school requires that she gives them a new medical certificate, as every three months, they want a proof that she's still sick. […] we have to call the school director again and explain again that she's sick … […] regarding the school, we are a bit angry.” (Mother of an 18-year-old girl)

Being different

The majority of adolescents reported that, since their symptoms first appeared, they felt that their classmates shut them out of the group, causing them to feel different. They reported that this feeling of being different was accentuated during

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leisure activities. Similarly, all parents reported that their children could not do the same activities as their peers, particularly going out with friends.

> “It's happened to me that I felt so bad or that I had to leave a party because it's really not going well, or that I have to leave for three hours to isolate myself for a while to try to get better.” (Male, 17 years old)

> “For her [my daughter], it's really hard because she can't party like the others […] because she can't go all the way as 17 is the age when one has to have fun. I mean, you start going out, it's very hard to go through that as the others can do it and not her […]. She gives up her life and that is the difference compared to the others.” (Father of a 16-year-old girl)

Moreover, this difference with peers was also noticed in the relationships between the adolescents and their parents. At a time when adolescents should decrease their dependence on parents, the majority of parents claimed that their child had become physically dependent on them. Moreover, some of them reported that they had grown closer to their adolescent child compared to when they were younger. While parents liked this, adolescents did not accept it as well:

> “She [my daughter] became like a baby, and sometimes I liked it. When she had pain, I extended a little bit more those intensive close moments with my child. But when she had no pain, I didn't exist for her of course. But when she was in pain, I went in her bed, next to her. I liked it.” (Mother of a 17-year-old girl)

Adolescents were very concerned about the attitude of their friends towards them: they did not want to look different from them and see their friends act differently with them. So they tried to hide their symptoms.

> “I didn't want people to treat me differently because I have a stomach-ache. I'm like everybody else. I take it on me. […] I've always wanted people to treat me like everybody else.” (Male, 17 years old)

> “What is always a problem for me, are those friends who change their behaviour. It makes me not want to see them or hear them say ‘watch out’” (Male, 15 years old)

Hiding the symptoms

Analysis put forward a discrepancy between adolescents' and their parents' views on coping with their emotions. Not spontaneously discussing symptoms with their parents and friends and continuing to smile were two strategies adolescents used to hide their suffering, avoid causing their parents to worry, and prevent their friends from acting differently towards them.

> “We always come with a smile. We can't come crying every day, or with a tired face, I mean we smile because we have to smile.” (Female, 15 years old)

Adolescents found that their parents discussed their symptoms too much, particularly with their friends.

> “I think that they [parents] should sign a confidentiality clause like doctors!” (Male, 15 years old)

> “I had the impression that it was my mother who was sick … rather than me.” (Female, 14 years old)

However, all parents explained that they did not discuss it sufficiently with their family and friends. This lack of communication was a burden for all parents, making them feel lonely and abandoned. This feeling of loneliness was accentuated by the impression that no one else experienced the same problem and, thus, could not understand it. Many of the parents expressed the need to share their feelings by joining support groups such as parents' associations and to share their experience with other parents who were facing the same problem. Moreover, they reported that their friends and even their family were often so concerned with their child's symptoms that they never inquired about the parent's health.

> “We are very lonely as a parent -at least for these diseases that we don't know- and for an evening like this evening [i.e. FG] there should be meeting places, places where parents can exchange their concerns, because we don't know whom to discuss it with.” (Mother of a 16-year-old girl)

> “I also felt many things: I was tired and everybody was worried about my daughter and I felt exhausted and exhausted and exhausted.” (Mother of an 18-year-old girl)

In fact, loneliness was not brought up in the recounting of adolescents' experiences. The adolescents explained that, even if they felt rejected by some friends, their close friends were still there for them. They claimed that unlike their parents, they did not need to discuss their symptoms, adding that just their close friends' presence helped them feel better and cheered them up:

> “I made a new circle of friends but only those who were close all the time really understood and helped me carry on … Otherwise, I think that if I hadn't been helped I wouldn't have made it.” (Female, 17 years old)

Priority to adolescent's health

Family life has been reorganized around the adolescent and the management of the symptoms. All parents reported that they gave more importance to their child than to themselves. Sometimes, this was at the expense of their own health.

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> “It's interesting because, when we are talking about parents' problems, we are first talking about our children. It's so natural not to talk about ourselves” (Mother of a 15-year-old boy)

> “We just take some painkillers and get on with it, without saying ‘I feel bad’ or ‘I'm sick’, because we have to be here for the child …” (Mother of an 18-year-old girl)

Because they had to spend so much time taking care of their child, parents noticed a decrease in their contact with their other children. Adolescents also described a difference in their parents' behavior.

> “Sometimes, I feel I'm a little bit too much in the first position because I have four siblings.” (Female, 16 years old)

The adolescent's condition also had an impact on the relationship between parents, although the experiences varied. Some parents discussed how disagreements about the approaches to take in managing their child's symptoms had created difficulties in their relationship. In contrast, other parents explained that the child's condition had caused them to grow closer together as a couple:

> “We experienced a lot of tension in our relationship and, deep inside, we knew that, in any case, [name of the adolescent] knew that it was because of him.” (Mother of a 16-year-old boy)

> “We grew closer -my wife and me.” (Father of a 15-year-old boy)

To observe the suffering of their child was extremely difficult for all parents. Some of the parents reported that, sometimes, it was easier for them not to see their child. Others added that they felt guilty for having caused his/her pain:

> “I was so happy when she left [for holidays]. I couldn't stand witnessing her suffering anymore and the fact that she was gone was easier for me.” (Mother of an 18-year-old girl)

> “I felt very guilty when saying to myself that I gave birth to a child who is suffering and I said to myself that, if I had not given birth to this child, she wouldn't be suffering, and I wouldn't be suffering and my husband wouldn't be suffering.” (Mother of a 13-year-old girl)

To relieve their child from his/her distress, all parents wished to attempt everything they could. Their main concern was to seek a solution for their child's symptoms and to consolidate their role as parents. However, all of them reported that, by doing so, they also wanted to relieve themselves of the feeling that they were powerless to cope with their child's illness:

> “She gets as many as she wants, I always give her lots of massages and it doesn't change anything. She will always have pain, but it was the only thing I found to be … to do something … to feel like a *mother*, to be useful …” (Mother of a 16-year-old girl)

> “We really ask ourselves how we can help because we don't always know how, and sometimes it's hopeless because we don't necessarily have a solution.” (Mother of a 15-year-old girl)

Discussion

This qualitative study presents the experiences and impact of symptoms of ten adolescents with MUS and sixteen parents. Four main themes emerged from the analysis: disbelief, appearing to be different from one's peers, concealing symptoms and priority to adolescent's health. Transcending these themes was a core issue: a discrepancy between adolescents' and their parents' strategies to cope with their symptoms. Adolescents explained not feeling a need to discuss their symptoms with their parents or friends. Indeed, they did not want to appear different from their peers therefore concealed their symptoms and avoided discussing them, which are two strategies to deal with this situation. For them, only the presence of their close friends provided sufficient emotional support. The importance of emotional support provided by friends has been highlighted in studies on adolescents with chronic diseases (Graetz, Shute, & Sawyer, 2000; Herzer, Umfress, Aljadeff, Ghai, & Zakowski, 2009; La Greca et al., 1995; Peters, Nawijn, & van Kesteren, 2014). Two studies (Graetz et al., 2000; Peters et al., 2014) emphasized different kinds of support, where family members on the one hand provided more tangible support than friends who, on the other hand, provided greater emotional support. However, our results also highlighted the adolescents' distress due to the disbelief from their “non-close” friends and classmates and their feeling of being excluded from the group because their inability to participate in group activities. A study on adolescents suffering from chronic pain reported the same feelings and failure to participate in activities (Forgeron, Evans, McGrath, Stevens, & Finley, 2013). The authors suggested that clinicians encourage adolescents to maintain a more active role in their friendships by initiating activities in which they felt they could participate and together find concrete ways to describe their symptoms. This might improve their ability to communicate their condition in a way their friends could understand.

Despite their children's opinion, parents mentioned the need to discuss their adolescent's condition and their experiences with their child and friends. The parents' desire to meet other parents who face the same problem by joining support groups was raised. We found no mention in the literature of advantages and disadvantages of parents of adolescent with MUS joining a support group. In fact, the benefits for parents in alleviating their loneliness and discussing their child's symptoms by joining a support group are open to challenge. Indeed parental behaviors have frequently been linked to the development or

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maintenance of symptoms in their child. Janssens et al. found that parental overprotection was linked to the presence of MUS in adolescents (Janssens et al., 2009), where Walker et al. showed that children reported significantly more complaints when their parents gave attention to them than when the parents were able to direct the child's attention away from their complaints (Lynn S. Walker et al., 2006). It is conceivable that such support groups may increase parents' attention to the symptoms and thus exacerbate the situation. Therapeutic groups may be the way to take into account the parents' need to exchange their views and feelings, while avoiding a reinforcement of adolescents' symptoms. A recent study that was undertaken to assess the feasibility and success of a specific educational intervention involved two groups of parents of adolescents with chronic illness. Like ours, this study highlighted parents' loneliness and need to exchange experiences with other parents who were undergoing similar problems (Akre, Ramelet, Berchtold, & Suris, 2014). The authors also reported that the subjective benefits that these parents would receive included a new view of their relationship with their child and, in turn, change their perspective of their situation. In many ways, MUS have an impact on different aspects of relationships. Confidence between adolescents and their entourage was affected by the disbelief in the diagnosis by the family or friends. The adolescents felt rejected by the group, parents' relationships with their adolescents became either closer or strained and parents frequently neglected their own health as they concentrated their attention on their adolescent's health. Therapeutic peer-to-peer support appears to be welcomed by parents. It is in line with the social cognitive theory – where people learn not only from their own experiences, but also by observing the actions of others and the results of those actions. Peer-to-peer support can be applied readily to counseling interventions for disease prevention and management (Glanz & Bishop, 2010). Various psychological interventions in adolescents with MUS were assessed, but the most relevant was the Cognitive Behavior Therapy (CBT) (Chiou & Nurko, 2010; Creed, Henningsen, & Fink, 2011). CBT is based on the complex interactions between thoughts, feelings and behaviors with the aim to learn better-coping and problem-solving skills, identification of triggers and reduction of maladaptive reactions to them (Chiou & Nurko, 2010). Over the years, several studies undertaken to confirm the efficacy of such interventions in children and adolescents concluded in their main findings that CBT is a useful intervention that should involve adolescents and their parents (Chiou & Nurko, 2010; Creed et al., 2011; Geist, Weinstein, Walker, & Campo, 2008). A possible way to combine the different methods suggested above (intervention group, peer-to-peer support), could incorporate sessions with the adolescent, the family and a peer-to-peer support group based on a CBT approach. During the CBT sessions, parents received training in ignoring nonverbal pain behaviors, redirection of children activity after pain complaints, use of positive and negative reinforcement or encouragement of positive coping skills (Chiou & Nurko, 2010). It helped them deal with their fears regarding their child's illness.

The main limitation of our study was the participation rate. Of the ninety-five adolescents contacted for participation in our study, only ten agreed to participate. The majority of adolescents who declined to participate explained that they no longer had any symptoms. As the literature has shown, MUS are usually transient and self-limiting. Thus, only a minority of adolescents have persistent MUS with significant distress and impairment. A good example of cases of transient and limited MUS was seen when examining the poor participation rate (2/57) among adolescents who were recruited in the gastroenterology clinic. On the other hand, six adolescents who declined to participate explained that they were too impaired and already devoted all of their time to managing their symptoms. Thus, our sample describes adolescents with persistent MUS and with a significant impairment, but who still can participate in activities. So, even if our sample of participants was not representative of the entire spectrum of MUS, it probably represented the majority of patients who are found in primary care and require prolonged medical care. We conducted three FGs of which two gathered only two adolescents in each group. According to the literature, four to six participants is the optimum size for a FG with children (Heary & Hennessy, 2002). The risk with a smaller group is that the discussion will resemble parallel interviews, rather than a dynamic group interaction. However, a literature review found no empirical studies that investigated the role of group size in FGs with children of any age (Heary & Hennessy, 2002). Moreover, in each FG we conducted, we observed a good dynamic in participants' interactions.

Because there is little in the literature about MUS in adolescents and their parents, we based our discussion on various studies of adolescents who suffered from chronic illness or pain. Given the fact that adolescents included in this study suffered also from a chronic condition because they were required to have had their symptoms for a minimum of six months, we postulate that some results could be comparable. However, previous studies highlighted some differences between adolescents with MUS and those with chronic explained illness. MUS adolescents were more likely to demonstrate failure in social functioning and perceived their health as poorer than other adolescents with chronic explained diseases (Kashikar-Zuck et al., 2007; Suris, Belanger, Ambresin, Chabloz, & Michaud, 2011). Further research is needed to investigate differences in illness perceptions and daily life between adolescents with unexplained conditions and those who have explained conditions, as well as the impact of the lack of explicit diagnosis.

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Conflict of interests

None to declare.

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A qualitative study of adolescents with medically unexplained symptoms and their parents. Part 2: How is healthcare perceived?

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A B S T R A C T

Medically unexplained symptoms (MUS) are common among adolescents and an important cause of clinical visits. This study sought to understand the experiences with, and perceptions of, the healthcare of adolescents who have MUS and their parents. Using a qualitative approach, six focus groups and two individual interviews were conducted with a total of ten adolescents and sixteen parents. The participants were recruited in a university hospital in Switzerland. A thematic analysis was conducted in accordance with the Grounded Theory. Six main themes emerged: needing a label for the symptoms, seeking an etiology to explain the symptoms, negotiating the medical system, medication and treatments, interactions with doctors, and the inclusion of parents during consultations. Transcending these themes, however, was the need for good communication between the adolescents, their parents and the clinicians. When explaining the symptoms, clinicians should make sure to discuss the results, investigations and lack of organic origin.

Introduction

Many adolescents who consult in primary care experience physical subjective symptoms for which physicians can find no corresponding objective findings after appropriate medical assessment or explanation on the basis of any known organic disease. Typically, such symptoms are called medically unexplained symptoms (MUS).

Previous surveys highlighted different prevalence rates among adolescents. These ranged from 3% for stomachaches to 46% for headaches with a female predominance (Bohman et al., 2012; Dhossche, Ferdinand, van der Ende, & Verhulst, 2001; Janssens, Oldehinkel, & Rosmalen, 2009; Janssens et al., 2011; Steinhausen & Winkler Metzke, 2007). Although the majority of MUS are benign, transient, self-limiting conditions that have no significant impact on functioning or wellbeing and need no further medical attention beyond one or two consultations (Fink, Rosendal, & Olesen, 2005; Mayou, 1991; Swanson,

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Hamilton, & Feldman, 2010), some patients who have chronic or multiple symptoms pose a serious challenge to healthcare providers and health systems (Verhaak, Meijer, Visser, & Wolters, 2006). Indeed, clinicians experience difficulties managing these patients and communicating with them, mainly because they misunderstand the patients' needs and worries (Cruz, Chudleigh, Savage, & Kozlowska, 2014; Epstein et al., 2006). Medical teams, although usually very competent with regards to organic illnesses, often lack a framework and language for thinking of and talking about functional somatic symptoms. Also, they often do not respond by inquiring further into the patient's experience of illness or validate the patient's distress (Epstein et al., 2006).

Furthermore, previous literature has reported a tendency of clinicians to consider MUS as minor symptoms and to reject the explanations presented by their patient. Clinicians tend to assume that normal results of tests and exams are sufficient to reassure the patient (Kirmayer, Robbins, Dworkind, & Yaffe, 1993; Nunes, Ventura, Encarnacao, Pinto, & Santos, 2013; Rief, Heitmuller, Reisberg, & Ruddel, 2006). However, the lack of a specific somatic diagnosis may raise a concern that their doctor may be missing some medical problem (Garralda, 1999; Geist, Weinstein, Walker, & Campo, 2008). For this reason, many patients seek additional medical advice and investigations. Hence, these patients are at high risk of unnecessary investigations, referrals, and treatments with secondary iatrogenic effects (Hatcher & Arroll, 2008). Over-investigation of MUS has also been linked to physicians feeling helpless (Hatcher & Arroll, 2008; Nettleton, 2006; Ring, Dowrick, Humphris, & Salmon, 2004).

In this context, it is essential to understand the expectations and needs of adolescents with MUS when they are seeking healthcare, in addition to taking their medical history. Despite a strong clinical demand, to our knowledge no research has been undertaken to better understand experience with and perceptions of the healthcare of adolescents with MUS and their parents. By using a qualitative approach, this study seeks to consider the experience of adolescents and their parents with regard to MUS in order to help clinicians improve the management of these patients.

Methods

We decided to use the focus group (FG) method as our primary research tool. FGs are particularly useful for exploring people's opinions, which are often difficult to investigate with other qualitative approaches. In separate groups, adolescents and parents had the opportunity to express themselves freely about their experience.

A total of sixteen parents and ten adolescents aged 12–20 years, who had been presenting MUS for at least six months, were interviewed. Six FGs were conducted with a total of fifteen parents and nine adolescents. Because two participants (a mother and her daughter) were unable to attend their scheduled FG, they were interviewed individually. Although FGs and individual interviews are very different research methods and can reveal diverse data (Peterson-Sweeney, 2005), analysis showed quite similar data emerging from both methods in this case. Hence we decided to include these data in our analyses. The characteristics of the participants and FGs are described in Tables 1 and 2.

MUS were defined as any current somatic complaint that has been reported by patients, been lasting more than six months, and for which no definite medical diagnosis can be found despite physical examination and appropriate investigation. The FG discussions lasted 60–90 min and were audio-recorded. The detailed description of the methodology has been published elsewhere (Moulin, Rodondi, Ambresin, & Suris, 2015).

All participants received a cinema gift-card in appreciation of their participation. Approval for the research was obtained from the Cantonal Ethics Committee.

Data analysis

Recordings were transcribed verbatim anonymously. The transcripts were read several times and coded according to a thematic analysis process. This involved the extraction of themes from participants' discourse according to the Grounded Theory principles in order to remain as close as possible to participants' experiences (Collingridge & Gantt, 2008). The different codes were compared continuously throughout the entire analysis to detect similarities and differences. They were then grouped into broader categories and analyzed to determine the elements that were relevant to the research questions. Analyses were undertaken by the first author, and systematically examined by the co-authors. In case of discrepancies between authors, the themes were discussed until a consensus was reached. The citations used in this paper were translated from French into English by the first author and verified by the co-authors.

Results

The results highlighted six categories of concern. For some aspects, these implied differences between adolescents' and parents' perspectives and ways of experiencing MUS.

Needing a label for the symptoms

Adolescents and their parents found it difficult to accept the lack of a diagnosis and medical explanation for the symptoms. They explained that having an established name for a disease could help finding strategies and solutions to cope with the symptoms:

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Table 1
Participants' characteristics.

Parents (n = 16)	
Mean age (years)	47.62
Range	38–55
Relationship to adolescent:	
- Mother	11
- Father	5
Marital status:	
- Married	11
- Separated/divorced	4
- Other (unspecified)	1
Recruitment clinic:	
- Adolescent health	9 (included two couples)
- Gastroenterology	5 (included one couple)
- Orthopedics	1
- Rheumatology	1
Adolescents (n = 10)	
Age (years)	
- Mean	16.0
- Range	14–19
Girls/boys	7/3
Siblings	
0	2
1	3
2	1
3 or more	4
Education level:	
- Mandatory school	3
- High school	5
- Apprenticeship	2
Symptom's duration (years):	
- Mean	3.75
- Range	1–7
FDI score (/60):	
- Mean	25.7
- Range	14–38
Recruitment clinic:	10/95
- Adolescent health	6/26
- Gastroenterology	2/57
- Orthopedics	1/9
- Rheumatology	1/3

FDI: Functional Disability Inventory.

> “It's not easy to live with something not knowing what it is. If we had a name for it, it would be easier to find solutions than not having one.” (Female, 15 years old)

The desire for explanations was sometimes so strong that some parents even wished that the symptoms were due to a serious pathology. With a well-known pathology, parents would feel that their family and friends could better understand the

Table 2
Focus groups' characteristics and list of symptoms.

FG[a]	Adolescents' age	Adolescents' gender	Symptoms	Parents' participation to the study
A1	18	F	Abdominal pain	Mother
A1	16	F	Polymyalgia	Mother and father
A1	16	M	Knee pain	Father
A1	18	F	Dizziness, pelvic pain	Mother
A2	14	F	Joint pain	Mother
A2	15	M	Dizziness, headache	Mother and father
A3	15	F	Foot pain	Father
A3	17	M	Abdominal pain, nausea	Mother and father
A4	15	F	Back pain, joint pain	Mother
Adolescent who participated without their parents				
A1	19	F	Abdominal pain	None
Parents who participated without their child				
P2	15	F	Overtiredness, joint and muscle pain, dizziness	Mother
P2	15	F	Hyperphagia	Mother
P3	17	F	Abdominal pain, headache, overtiredness	Mother
P3	13	F	Abdominal pain	Mother

[a] A = adolescents' focus group, P = parents' focus group.

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condition and express compassion. In fact, both parents and adolescents reported having difficulty in sharing and explaining symptoms to their family and friends, because they did not correspond to a named condition. For the adolescents, having a clear diagnosis could alleviate the disbelief of their peers when discussing the symptoms:

> “This is the difference: When you can say what you have exactly, you can be sure that others [peers] can understand a little more.” (Female, 18 years old)

Adolescents also reported that having a name for their disease would relieve them from feeling lonely and would help them meet other adolescents who have the same condition:

> “When they [clinicians] provide a label, it reassures me. I am not the only one in this case. The fact is a bit easier to accept, and, above all, if you are not alone in this case, it helps, because having pain without an explanation is annoying.” (Male, 17 years old)

Parents and adolescents expressed different feelings concerning the healthcare system with regard to the lack of diagnosis. Some understood that doctors did not have sufficient knowledge of all diseases, especially rare diseases like MUS. Thus, for a minority of parents, searching for information in books or on the Internet was a normal way for them to help doctors find a diagnosis and solutions to the symptoms:

> “My wife never stops reading research. She does the research […] because we have to … Is it really only the responsibility of the healthcare system to know all about what I believe is a rare disease?” (Father of a 15-year-old boy)

However, some parents and adolescents felt distressed and angry towards the healthcare system because doctors had failed to diagnose their condition. They felt abandoned by the system. Some even believed that doctors were incompetent.

> “I'm angry against all these clinicians who are unable to take us seriously […]. I have cried for hours at home, feeling abandoned by the medical system […]. We [my husband and me] also understand that the medical system does extraordinary things, […] it cures, but on the other hand it seems powerless to cure these diseases of which we don't know much” (Mother of a 16-year-old girl)

Seeking an etiology to explain symptoms

The lack of a medical explanation led parents and adolescents to find a justification for the symptoms on their own. For a majority of them, the symptoms were caused by biomedical factors:

> “It was stomach-aches after a gastro-enteritis from which she [my daughter] never recovered, since four years now.” (Mother of a 17-year-old girl)

However, for a minority, psychosomatic factors — mainly anxiety — explained the presence of symptoms.

> “I have knee pain since a long time, linked to anxiety […]. It is a psychosomatic pain because it is present but it depends on the moment …” (Male, 16 years old)

Nevertheless, no matter what factors parents and adolescents found to explain the symptoms, the majority was worried that the symptoms would evolve into a serious disease:

> “It can be worrying to think that it can be a simple stomach-ache, but maybe it can transform into this or become that … so sometimes it's worrying me anyhow …” (Male, 17 years old)

However, a minority of adolescents explained that not having a diagnosis was also reassuring because if they had something serious, doctors would have found it.

> “Because they [clinicians] found nothing, I think that if it was something serious, if I really had a problem in my spine or something like that, I think that they would have found something before. After five years of research I cannot see what could happen to me …” (Female, 15 year old)

Negotiating the medical system

All adolescents and parents reported that, because no diagnosis or solutions were found, they had had multiple physician visits, and many specialist consultations. Whether this was due to their own initiative or to their doctor's recommendation, all adolescents explained a feeling of wandering around.

> “I had the feeling to be like a ball that they [clinicians] threw from left to right […]. One time it was this, another time it was more that, another time it was this again.” (Male, 17 years old)

In addition, all adolescents complained that the main problem with changing doctors was the lack of communication between them. Indeed, they complained that they always had to repeat the same things about their symptoms and answer the same questions.

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> “At the hospital you see plenty of doctors. You have to explain the same story over and over from the beginning, and then you see another doctor, and you continue to explain the same story. After that, you go to another hospital and, again, you explain the same story. So that's it. They don't believe us.” (Female, 15 years old)

Parents believed that coordination between healthcare providers was necessary to communicate regarding information about already performed investigations:

> “[Since my daughter was taken care of in this clinic] I only have to take care of my daughter and I don't feel obliged to have to listen carefully and try to make connections like I used to, because it's not my work to do that.” (Mother of an 18-year-old girl)

In addition to a coordination of the efforts of each health professional involved in their child's care, parents also wished to have a reference person to address if they had a problem:

> “I think that we feel lonely despite all this care. When she's not doing well I still don't know where to go to” (Mother of a 16-year-old girl)

Both parents and adolescents reported that doctors conducted many examinations to find the cause of the symptoms, but expressed different opinions. Some adolescents reported that when doctors conducted many investigations, it meant that they had no idea about their condition or its cause. They also stated that they did not like to visit their doctor because they were confronted with the reality of their condition:

> “It was difficult for me to accept what I had and, thus, I hated consulting doctors because I did not want to … I did not want to have the proof that I was sick” (Female, 16 years old)

On the other hand, many adolescents and parents explained that, when they visited their doctor for a control or an investigation, they were reassured.

> “All the time that I spent at the doctor's, I loved it, because every time I felt that he was going to save my child. So I loved going there. He told me that he was going to do something, to look for something else … so, every time I was enthusiastic to know what he would suggest.” (Mother of a 17-year-old boy)

Although some parents declared that they had fought with health professionals to obtain more investigations, others reported that they sometimes felt ashamed of consulting them again with their child.

> “You have to ask for investigations, because if you don't ask you don't get it. Often we have to bang our fiston the tableto obtain further investigations”. (Father of a 16-year-old girl)

> “Finally when they [clinicians] perform exams and nothing is wrong, and … I'm ashamed to say that there is always something …” (Mother of a 13-year-old girl)

Medication and treatments

Medication

Some parents felt that doctors should prescribe more medication for their child, especially analgesics. In fact, a minority of parents admitted that they were so distressed to see their child suffer that they sometimes gave drugs to their child without a medical recommendation:

> “They [clinicians] had always refused to give her [my daughter] medication at home […]. For me, it is intolerable. I can't see her like that, lying on the floor and crying … so I give her tramadol [analgesics] without medical advice […] I feel guilty with that and I don't dare telling the doctors … my daughter does not tell them either. It's a secret between her and me.” (Mother of a 16-year-old girl)

The majority of adolescents supported that, but it was interesting to note that some adolescents reported that doctors should prescribe fewer drugs because over time, they become less effective and have important side effects.

> “I think that medication is useless. It makes you worse …” (Female, 19 years old)

> “Drugs have an effect on me for a while but after I can't use them anymore because they don't have any more effect on me.” (Female, 14 years old)

Psychiatry

Parents had diverging opinions regarding the efficacy and necessity of psychiatric treatment. Some of them were reluctant to have their child consult a psychiatrist because of the socially negative connotations associated with it. Other parents' reluctance arose from their assumption that it indicated that a psychological condition was the cause of the symptoms. On the contrary, other parents encouraged their child to consult a psychiatrist to discuss their condition and experiences.

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> “We allowed her to consult a psychiatrist to take some weight off of her by talking about her experience, telling all the things that she accumulated during these months.” (Mother of a 17-year-old girl)

> “I ask myself if the medical community really realizes the negative medical history that these children who consult a psychiatrist will have in the future.” (Father, 16-year-old boy)

All adolescents explained that when their doctor recommended that they consult a psychiatrist, they disagreed with the suggestion. They believed that if their doctors had recommended this, they did so because they did not believe the reported symptoms.

> “The third [clinician] still doesn't know. So he refers you somewhere else, but somewhere else they [clinicians] tell you that your problem is psychological. So you should consult [a psychiatrist] … its painful! […] So you decide not to consult because you know very well that it is not psychological. So, you continue to look for doctors who will want to believe you.” (Female, 15 years old)

Those who consulted a psychiatrist typically reported that doing so did not help alleviate the condition, but sometimes helped them understand how to cope with the symptoms.

> “I do not think that talking about it will help me feel better. On the other hand, I think that talking about it will help me live with my pain.” (Female, 15 years old)

Complementary and alternative medicine

The majority of parents felt abandoned by the traditional healthcare system. They felt desperate because nobody had found a solution to their child's symptoms. Doubts about the competencies of the medical system and the absence of solutions led them to try complementary and alternative medicines (CAM):

> “I have also tried many different kinds of parallel techniques. I think that I have tried everything, because when you are desperate …” (Mother of a 13-year-old girl)

They added that by using these methods, they felt that the therapist had listened and understood them, contrarily to their experience with conventional medicine.

> “I was more satisfied with alternative therapies where I had the feeling that someone was listening to me. […] When you do not have a treatment, just listening can be a relief.” (Mother of a 13-year-old girl)

Adolescents did not unanimously support the use of these methods. In addition to considering CAM as useless and strange, they stated that they did not benefit from them.

> “I do not really believe in it, Chinese medicine. For me it's not … […] I don't believe in it. I tried it once, but it's not for me. That's finished for me.” (Female, 15 years old)

However, even if parents were aware that their child had not experienced any benefits from CAM, they observed improvements in their child's condition:

> “She [my daughter] doesn't feel that, for example, acupuncture, makes her feel better, but when I talk with her on the phone, I hear her energy.” (Mother of a 17-year-old girl)

However, two adolescents agreed with their parents on the benefits and efficacy of these methods.

> “It was extremely useful, homeopathy, natural medicine. Incredibly useful on my doctor's recommendation.” (Male, 15 years old)

Nevertheless, for those adolescents who experienced CAM, whether they believed in it or not, osteopathic manipulative treatment appeared to be generally more accepted and brought more benefits than other CAM. Relaxation techniques, such as yoga, were also popular:

> “Now, she [my daughter] has started to consult an osteopath again because she found someone specialized in the manipulation of the jaw. It's more hands-on. So, she agrees to do it. She rejected all other complementary medicines.” (Mother of a 17-year-old girl)

Interactions with doctors

The majority of adolescents explained that they were not only distressed because doctors had failed to diagnose their condition or prescribed unsuccessful treatments, but also because doctors had failed to understand their problems.

> “Finally, they [clinicians] try one medication - then another. They try another and if it still doesn't work, they try another. Then at the end they don't know what it is … they find nothing. You don't feel understood” (Male, 17 years old)

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Furthermore, most adolescents and their parents felt that at a certain point health providers did not believe them. This was most acutely felt when doctors explained the possibility of psychological influences on their symptoms.

> "They [clinicians] do not believe us [...]. In the beginning, they look for something, but, after a while, they say that maybe I invented it or that it is in my head." (Female, 15 years old)

All adolescents were distressed because their doctors rarely enquired about their daily life and emotional impact. They wanted to discuss this more, instead of always discussing the quality of their symptoms.

> "Doctors ... I feel that they give a medication and, after that, they get rid of us ... and here [name of the clinic], there were the first doctors who looked for something else than giving medication. [...] Yes, who tried to take care of my morale first." (Female, 16 years old)

In addition, a majority of adolescents reported that they did not always understand the explanations that were given by health professionals. Some of them confessed that they did not even understand the diagnosis or the lack of diagnosis. In most cases, they did not understand why some investigations were conducted:

> "Doctors should try to better explain what we have, because we do not understand a thing." (Female, 14 years old)

> "I think that the tests that they do ... I think that it would be nice if they explained why they do them" (Male, 15 years old)

Inclusion of parents during consultations

All adolescents indicated that the presence of their parents did not disturb them. However, during some consultations, they preferred to be alone with the health professional to discuss topics of a personal nature:

> "I think that I talk about my problem more easily if my mother is not there. It is easier for me to talk because of medical confidentiality. If I say something personal, it will stay between me and my doctor and my mother will not hear about it" (Male, 17 years old)

Unlike their child who stressed the importance of medical confidentiality, most parents believed that doctors adhered to this principle too strictly and wished to have more feedback following consultations, especially consultations with the psychiatrist, in which they were not included.

> "Because of the medical confidentiality, doctors cannot talk with parents anymore so that we can help a little bit more the children – our children." (Mother of a 15-year-old girl)

However, even if adolescents were not disturbed by the presence of their parents during consultations, they complained that their parents often monopolized the conversation and were not entirely accurate in what they told the health professional.

> "Actually she talked more than me. I almost never talked because it was only her who talked [...] sometimes; it was not totally true [...] she talked, talked. She said things such as that I had pain, things like that. But half of what she said was sometimes right, but it was not exactly the truth." (Female, 14 years old)

All parents deplored the doctors' failure to listen. Indeed, they explained that parents spent a lot of their time with their child and, thus, had relevant information to provide. Moreover, they added that their child was often embarrassed and reluctant to describe all problems to the doctors. Thus, most parents believed that it was important that they participate in the medical consultations, with or without their child, to explain their perceptions of their child's condition:

> "It is good to listen to the teenager, but I think that listening to the parents is very important. [...] Even if we have a lot of medical appointments, he [doctor] does not spend as much time as I spend with my child at home" (Mother of a 13-year-old girl)

Discussion

Adolescents with MUS and their parents reported encountering many challenges with the healthcare system. In line with previous studies (Cruz et al., 2014), our samples confirmed that families have experienced, and continue to experience, significant stress and anxiety. These are caused by the impact of life events, interactions within and outside of the family, difficulties in negotiating the medical system and the attempt to receive an explanation that makes sense to them. One core issue that our analysis uncovered is the importance of good communication among adolescents, their parents and health professionals. It can have a direct impact on adolescent's and parent's stress and anxiety.

For many adolescents and parents, the lack of diagnosis was difficult to accept. Indeed, in addition to being an obstacle to sharing with people and receiving sympathy, the absence of a somatic diagnosis has caused adolescents and their parents to mistrust the clinicians' skills. Guthrie (2008) made the same observation stating that, in most cases, patients perceived the

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explanations that their clinicians gave them as a rejection of their suffering. This has led the patients to question doctors' competency. In some cases, conflict may ensue. Moreover, our results emphasize that ascribing a psychiatric origin to the adolescent's symptoms changed their trust in their doctor and enhanced the feeling of not being understood. Previously reported work has supported this and indicated that parents are often anxious about their child's illness and may not understand why psychological issues are being raised (Cruz et al., 2014). Therefore, we recommend clinicians to assure the patient that the condition is being taken seriously and precede this with a careful history taking and a detailed physical examination (Nunes et al., 2013). They also should provide an explanation for the symptoms, integrating a bio-psychosocial approach. Thus, as our results have emphasized, and in line with previous studies (Guthrie, 2008), patients are convinced that their symptoms are real and therefore must have a medical explanation. It has been shown that the use of metaphors to explain the symptoms is particularly useful in ensuring an understanding of the bio-psychosocial approach but also removing any sense of responsibility (Guthrie, 2008). Clinicians should also explain to patients and their families that considering the presence of a psychiatric disorder does not mean that their symptoms are imaginary or simulated, but simply that their mental status can exacerbate and perpetuate symptoms (Barsky & Borus, 1999; Heijmans et al., 2011; Ibeziako & Bujoreanu, 2011). Antidepressants could help improve the symptoms in adults who have MUS and are used for adolescents in similar circumstances. However, the evidence for this remains limited in the age group (Eminson, 2007; O'Malley et al., 1999). Clinicians should also be careful to provide good explanations to parents and adolescents when prescribing them to avoid its misinterpretation as an indication of a psychiatric disorder.

The use of the MUS label also can contribute to this misunderstanding between patients and clinicians. Although the term MUS is preferred by many clinicians, because it does not imply any sense of psychological cause (Guthrie, 2008) and is scientifically neutral, many authors agree that it has negative connotations for patients (Creed et al., 2010). Using this label makes a negative statement and withholds from the patient a positive explanation for the symptoms. It may imply that the clinician is dismissing the patient because the former is unable to help. Use of "functional" as a label appears to be more acceptable to the patient. This term has the advantage of avoiding the "no diagnosis" of the "medically unexplained" and sidesteps the unhelpful psychological versus physical dichotomy that the MUS label implies (Creed et al., 2010).

Furthermore, telling adolescents and their parents that clinicians could not diagnose the condition is not effective and may even result in more medical care-seeking (Dowrick, Ring, Humphris, & Salmon, 2004; Olde Hartman, Hassink-Franke, Lucassen, van Spaendonck, & van Weel, 2009; Salmon, Peters, & Stanley, 1999) and can increase the levels of anxiety (Cruz et al., 2014). Indeed, almost all adolescents and parents reported that they underwent multiple investigations. Indeed, clinicians should pay attention when prescribing additional tests and investigations. Indeed, other authors have indicated that negative findings have provided little reassurance to most patients (Creed et al., 2010; Geist et al., 2008). Moreover, in line with the remarks of some participants, previous papers have stressed that over-investigations can suggest to the patient that the diagnosis is uncertain (Geist et al., 2008) and reinforce the patient's conviction that the condition has a biomedical explanation (Creed et al., 2010; Kingma et al., 2011; Rousseau et al., 2013). Thus, the challenge for clinicians is to find a balance between the proper investigations to avoid missing a possible organic cause, reassuring the patient and the family, and avoiding unnecessary repetitive testing, which may induce iatrogenic effects. While most parents reported that clinicians did not listen to them sufficiently and wanted to be more involved during consultations, the adolescents liked individual interviews. Geist et al. (2008) provided recommendations in which the importance of both individual and family interviews were highlighted. Individual interviews are important to ensure that adolescents can express themselves as freely as possible about their experiences and investigate emotional symptoms. Family consultations can provide an opportunity to discuss parent's emotional issues that may trigger the onset of symptoms or cause them to persist (Geist et al., 2008; Janssens et al., 2009; Kingma et al., 2011; Petanidou et al., 2012; Rousseau et al., 2013). In fact, a recent review suggested that parental decisions to seek healthcare for their children may reflect parental health attitudes, health beliefs and consulting behavior, rather than the children's needs (Shraim, Mallen, & Dunn, 2013). Moreover, engaging and working with the family to share common expectations is necessary before effective treatment can be undertaken (Garralda, 2010).

As explained elsewhere (Moulin et al., 2015), the main limitation of our study was the participation rate. Of the ninety-five adolescents invited to take part in our study, only ten agreed to participate. The majority of adolescents who declined to participate explained that they no longer had any symptoms. As described in the literature, MUS are usually transient and self-limiting. Thus, only a minority of adolescents has persistent MUS with significant distress and impairment. A good example of these cases of transient and limited MUS was evident in the poor participation rate (2/57) among adolescents who were recruited from the gastroenterology clinic. A small number of the adolescents who declined to participate explained that they were too impaired and already devoted all their time to managing their symptoms. Even if our sample was not representative of the entire spectrum of MUS, it probably represented the majority of patients who are found in primary care and who require prolonged medical care.

Our study emphasizes the fact that the difficulties in managing adolescents with MUS and their parents are due, in great part, to the lack of communication. Also, the absence of a diagnosis is an extra burden for the patient and the family. Clinicians should pay particular attention when explaining that nothing "wrong" was found and what that implies. Discussing functional symptoms is probably more acceptable to patients than is MUS. The MUS label has the advantage of avoiding the "no-diagnosis" one (Stone et al., 2002). The concept of Bodily Distress Disorder was also proposed. It could unite many functional somatic syndromes and some somatoform disorder diagnoses. Using this term seemed to be well-accepted by patients (Fink & Schroder, 2010; Fink, Toft, Hansen, Ornbol, & Olesen, 2007). Moreover, clinicians should be careful when referring their patient to a psychiatrist. Indeed, for the majority of adolescents and their parents, seeking help from a psychiatrist was

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stigmatizing and inappropriate. When families are referred to psychological services, they are often anxious about their child's illness and may not understand why psychological issues are being raised when their child presents with a physical problem (Kozlowska, English, & Savage, 2013). For this reason, clinicians should engage families from the beginning of the care of adolescents with MUS and good communication between clinicians, adolescents and their parents is a key issue (Kozlowska et al., 2013). Finally, it is important that parents be integrated in their child's care with a family-based interview. It is equally important that adolescents have some time alone during the consultation so that they may be heard.

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Conflict of interests

None to declare.

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