



## 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.

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### 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; Schaefer 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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