

## Coping in mexican adolescents with metabolic syndrome: a qualitative study

Afrontamiento en adolescentes mexicanos con síndrome metabólico: un estudio cualitativo

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### Abstract

This paper describes the daily coping strategies among Mexican adolescents diagnosed with metabolic syndrome (MS). Data were collected through a semi-structured interview, using a phenomenology perspective. Nine adolescents diagnosed with MS aged 12-17 years were recruited from a public hospital in northeastern Mexico. Three thematic categories were obtained in the interview analysis: experiencing an MS diagnosis, adapting to health care and treatment, and decision-making to cope with the disease. Adolescents receiving an MS diagnosis were able to overcome their initial -often negative- experiences, they were motivated to adhere to management and treatment plans with support from health professionals, and they were able to develop adaptive coping strategies. Results indicate that, with support, adolescents could adapt to new prevention, management, and treatment strategies.

**Keywords:** Metabolic X syndrome; adolescents; qualitative research; psychological adaptation; Mexico.

### Resumen

El presente artículo describe las estrategias diarias de afrontamiento entre adolescentes mexicanos diagnosticados con síndrome metabólico (SM). Los datos fueron recolectados mediante entrevistas semi-estructuradas, utilizando una perspectiva fenomenológica con nueve adolescentes con SM de entre 12 y 17 años, reclutados en un hospital público del noreste de México. El análisis de las entrevistas reveló tres categorías temáticas: cómo los adolescentes experimentan el diagnóstico de SM, cómo se adaptan a la atención de salud y tratamiento, y la toma de decisiones para hacer frente al padecimiento. Los adolescentes que recibieron un diagnóstico de SM fueron capaces de superar sus experiencias iniciales -a menudo negativas-, fueron motivados a adherirse a planes de manejo y tratamiento con el apoyo de profesionales de la salud, y fueron capaces de desarrollar estrategias adaptativas de afrontamiento. Los resultados indican que, con apoyo, los adolescentes podrían adaptarse a nuevas estrategias de prevención, manejo y tratamiento.

**Palabras clave:** Síndrome X Metabólico; adolescentes; investigación cualitativa; adaptación psicológica; México.

Recibido: 7 de septiembre de 2017

Aceptado: 11 de febrero de 2019

Publicado: 05 de septiembre de 2019

**Como citar:** Onofre-Rodríguez, D. J., Cueva-Luna, T. E., Peláez-Ballestas, I., Garza-Elizondo, M. E., & Benavides-Torres, R. A. (2019). Coping in mexican adolescents with metabolic syndrome: a qualitative study. *Acta Universitaria* 29, e2053. doi: <http://doi.org/10.15174/au.2019.2053>

## Introduction

In recent decades, the obesity epidemic in children and adolescents is the cause of diseases, like the metabolic syndrome (MS), that in the past only appeared in adults (Romero-Velarde *et al.*, 2016). Reports issued by the United Nations International Children's Emergency Fund (UNICEF) (UNICEF, 2012) indicate that Mexico ranks first in the world in childhood obesity and second in obesity in adults, only preceded by the United States. The prevalence of MS is between 38% - 55% in Mexican children, above the 95th percentile for age and weight and/or with acanthosis nigricans depending on the diagnostic criteria employed (Romero-Velarde *et al.*, 2016).

Using the National Cholesterol Education Program Adult Treatment Panel III (National Center for Biotechnology Information [NCBI], 2002) criteria, one of the most common criteria used for diagnosis of MS in both adolescents and adults, a diagnosis of MS is based on having at least three of the following five metabolic risk factors: 1) abdominal obesity with a waist circumference >40 inches for men or >35 inches for women, 2) blood pressure >130/85 mmHg, 3) a fasting triglyceride >150 mg/dl, 4) a fasting high-density lipoprotein cholesterol <40 mg/dl for men or 50 mg/dl for women, and 5) glucose metabolism abnormalities with a fasting blood sugar >100 mg/dl (NCBI, 2002).

The causes of MS are attributed to a combination of genetic and lifestyle factors, such as overeating and low physical activity (de Onis, Blössner & Borghi, 2010). MS management includes lifestyle changes such as improved eating habits and increased physical activity leading to weight loss, along with a pharmacological treatment of dyslipidemia, high blood pressure, and impaired fasting blood glucose as needed (López *et al.*, 2012). Unmanaged MS is associated with an increased risk of coronary artery disease, diabetes, and death (Gami *et al.*, 2007).

While studies of the epidemiology and risk factors for MS among adolescents are increasing (Ferreira, Sanchez, Netto-Oliveira & Fossati, 2009; López *et al.*, 2012); the subjective experiences of the growing number of adolescents diagnosed with MS, along with their adaptation, coping, and disease management strategies, remain unknown. Protective lifestyle changes require a *cognitive and behavioral effort* to respond to specific demands, which initially can be perceived as overwhelming (De Onis *et al.*, 2010). Understanding these experiences and coping strategies could significantly impact behavior change interventions.

A common framework for understanding coping is based on a transactional theory model proposed by Lazarus & Folkman (1984), in which stressful stimuli and coping are integrated. Coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984). Adolescents experiencing major life events must often cope with the stress of the event as well as common stressors faced by adolescents (e.g., deciding on a line of work or profession (Della-Mora, 2006), working to 'fit in' and find one's place, and feeling concerned with physical appearances due to physiological and morphological changes). One major life event might be related to his or her experience of dealing with MS.

According to this model, the primary response to a stressor, such as a disease diagnosis, is to evaluate its potential impact and one's capacity to manage that stress. This implies a subjective interpretation of the situation with a cognitive-affective response that enables the individual to choose a coping strategy (Lazarus, 1993). The strategies may be adaptive (i.e., those leading to stress reduction and positively impacting long-term health) or maladaptive (i.e., those that may reduce stress in the short term, but do not positively impact long-term health) (Holroyd & Lazarus, 1982).

Coping in adolescents with diseases or medical conditions has been studied from a quantitative view in the case of chronic pain, type 1 diabetes, and cancer (Compas, Jaser, Dunn & Rodriguez, 2012; Jaser *et al.*, 2012), HIV infection (Martinez *et al.*, 2012), pain in juvenile fibromyalgia (Kashikar-Zuck *et al.*, 2013), obesity and overweight (Puhl & Luedicke, 2012), and hopelessness and depression (Rodríguez-Naranjo & Caño, 2016); on the other hand, the experience of coping from a qualitative view has been reported in the case of cancer and the potential loss of fertility (Lam, Cohen & Roter, 2013).

However, as far as it is known, coping abilities and strategies among Mexican adolescents with MS diagnoses have not been studied. Given the burden of MS and its associated poor health outcomes in Mexico, it is critical to better understand how adolescents cope with this syndrome to inform improved disease management interventions. The objective of this research was to describe the daily coping strategies employed by Mexican adolescents with MS, specifically those regarding experiencing an MS diagnosis, adapting to health care and treatment protocols, and adolescent decision-making to cope with the disease.

## Materials and Methods

### Type of study

This qualitative study used a phenomenological approach (von Eckartsberg, 1998) to understand the daily experiences of adolescents diagnosed with MS.

### Sample selection and data collection

Nine adolescents (six boys and three girls), aged 12 to 17 years with MS, who were participating in an MS treatment protocol in a public hospital in northeastern Mexico were invited to enroll in the study by the principal investigator. The adolescents selected came from families unable to meet basic needs (insufficient familial income for food, health expenses, clothing, housing, transport, and education) and no health insurance (García-Justicia, 2013). Both parents were working and had a mean of 8.6 years of education (standard deviation of 1.4 years).

The treatment protocol consisted of comprehensive health care provided by a multidisciplinary team, including endocrinologists, nurses, psychologists, nutritionists, and social workers. The focus was on providing medical, psychological, nutritional, and health education orientation. At the time of the study, the patients had been in treatment for six months. Purposeful sampling, widely used in qualitative research, was used to identify participants with experience of MS (Palinkas *et al.*, 2015) within nine months, which was the maximum time required to identify adolescents via their medical records and, subsequently, contact them in a health center or at home, where they were invited to participate.

An interview guide that was reviewed by experts in the field and/or in the methodology was developed to corroborate the phenomenon. Open and uncategorized pre-established interviews were considered as suggested by Creswell (2009), since these allow participants to express their experiences without the influence of the researcher's point of view, showing that response categories were generated by the interviewee.

The interview guide was made up of eight trigger questions so that interviewees discuss the topic (Mertens, 2005). These questions focused on obtaining the description of daily coping strategies of Mexican adolescents diagnosed with MS. The interviews with the adolescents were conducted in Spanish and carried out by two researchers in a private room of the health center or in the adolescent's home. Adolescents were asked to reflect on their experiences with MS. These semi-structured interviews lasted approximately 45 min. Examples

of semi-structured interview questions were: *What can you tell me about your condition? What do you remember about the moment you found out you had SM?*

## Ethical criteria

Ethics approval for the research was obtained from the Research and Ethics Committee of the Department of Medicine, Autonomos University of Nuevo Leon and the Dr. José Eleuterio González University Hospital, Monterrey, Mexico (registration number EN-10-009). Written informed consent was obtained from parents or guardians, and assent was obtained from study participants after asking them to participate. Parents and adolescents were informed of the nature of the research and about the confidentiality of the study data and anonymity of the adolescents. To protect the participants' anonymity, quotes reported in this article are identified only by gender and age (e.g., M12, F12).

## Analysis

The interviews were recorded and later transcribed and analyzed by three investigators, using MAXQDA v11 software. Each transcript was read three times (mean), extracting keywords and significant phrases in the process. Data interpretation was performed through *free imaginative variation*, which consists of selecting the thematic categories to best capture the meaning of the adolescents' responses regarding their experiences with MS. This type of analysis is based on methods by Giorgi (1997), which consist of a first critical reading of the transcriptions to obtain a general sense of the content and, then, a second reading to select the units of meaning (data segments that show some aspect of importance with respect to the object of study). Subsequently, these units of meaning were grouped by common themes. Finally, the common themes were integrated into a consistent statement that captured the meaning of the responses. To ensure study rigor, the three researchers were multidisciplinary, and their different perspectives enriched the research process both in the data collection and analysis phase (Giacomini & Cook, 2000).

## Results

The characteristics of the adolescents are shown in table 1. The following thematic categories describing how adolescents cope with MS in their daily lives were identified from the semi-structured data: experiencing an MS diagnosis, adapting to health care and treatment, and decision-making to cope.

**Table 1.** Socio-demographic characteristics of adolescents with metabolic syndrome (MS).

Adolescent	Age (years)	Gender	School level	Diagnosis (Documented by an endocrinologist)
1	12	M	Primary	MS + <i>acanthosis nigricans</i>
2	14	M	Junior high	MS + <i>acanthosis nigricans</i>
3	15	F	Junior high	MS + polycystic ovaries + hirsutism
4	15	M	High school	MS
5	17	M	Vocational school	MS + <i>acanthosis nigricans</i>
6	14	F	Junior high	MS
7	16	M	High school	MS
8	13	M	Junior high	MS + <i>acanthosis nigricans</i>
9	13	F	Junior high	MS + <i>acanthosis nigricans</i>

M: male, F: female

Source: Author's own elaboration.

## Experiencing an MS diagnosis

Upon receiving an MS diagnosis, several adolescents described surprise or shock: "I was surprised. I did not understand what was happening" (M14); "I had no idea how bad it was" (M16). Some described traumatic emotions: "You want to die, you don't want to talk to anybody or to be with anyone, you just want to cry" (M15), or referred to a state of distress: "I'm confused... I can't hide my agony" (F15).

These responses may be related to the way adolescents received their MS diagnosis. Along with feelings of surprise were reports of the *seriousness* (F15) with which medical staff informed them about their condition or the drama of a mother upon hearing the diagnosis: "my mom broke down in tears" (M12).

Adolescents reported a range of experiences with respect to their awareness of their own health before the diagnosis. While some had an idea that something was wrong with their health, others were completely unaware, and confusion was a common response.

"It scared me to think I was seriously ill. I knew something wasn't right, and I expected I had something..." (M14).

"I had passed out and my mom rushed me to the hospital. The doctor told me I had MS. I was worried. I was in the hospital because I fainted, but then I got the diagnosis, and I was afraid" (F14).

"I only went to see the doctor because my period was late, and they told me I was sick... I didn't know what it was" (F15).

## Adapting to health care and treatment

In the process of coping with a new diagnosis, some adolescents reported understanding the need to comply with health care instructions. This is exemplified by reports of the following doctor's orders regarding their diet and treatment; in some cases, even other obligations such as school were affected.

"I need to eat and take my medicine regularly. I can't afford to say 'I don't want to do it'

--this is what I must do" (F13).

"Sometimes I have to miss school because I have an appointment with the doctor" (F14).

"If the doctors tell me to do something, I just do it..." (M14).

Many reported to be optimistic about the changes they were asked to make by health care professionals. Most adolescents reported having gained determination, confidence, and being more organized due to managing their condition.

"I finally started working out. It was my illness that helped me make this decision" (M14).

"I'm no longer afraid of being ill" (M16).

"I'll get used to eating well, and I'll lead a healthier life" (F14).

Seeing the positive aspects of potentially difficult situations helped some adolescents manage their emotions that otherwise might aggravate the problem:

"My blood sugar was low, and I had to eat a candy, and it was good because I no longer get to eat them often" (M12).

"I didn't realize that there was an easy way to take them [drugs]" (F15).

"...I went through a whole process of getting used to taking all the drugs" (M13).

Some adolescents reported a range of negative emotions due to their MS diagnosis. Different coping mechanisms were employed:

"There is no reason to get mad. There isn't much I can do about it, so I'm just stuck with it [MS]..." (F14).

"I just keep quiet and keep on going [...]" (M12).

## Decision-making to cope

In the process of acknowledging the diagnosis and treatment of MS, some adolescents decided on perseverance and finding opportunities to enjoy themselves. Two adolescents expressed:

"...Maybe I should take some things easy" (M17).

"There isn't much I can do besides following the doctor's orders and... keep doing the things I like" (M16).

Some adolescents reframed their way of thinking about the disease in order to stop seeing it as a traumatic event:

"Adapting to it [MS]... is just having to find a way to live a life" (M16).

"The illness is a part of my life. It's something you learn to live with" (F15).

Adaptation appears to inform adolescents' decisions about compliance with prescribed treatments and reliance on their best judgment to handle situations:

"I can say no when I'm offered something I shouldn't be eating" (M16, F13).

"Before soccer practice, I check my blood pressure and if it's high, I'll pop a pill" (M12).

"Sometimes when I can't do PE <physical education>, I try to find some other workout" (M17).

## Discussion

Coping with stressful health events is a complex phenomenon and is important to understand in adolescents to inform supportive management and treatment. In this study, the topics identified in adolescents' description of their coping strategies after an MS diagnosis included experiencing an MS diagnosis, adapting to health care and treatment, and decision-making to cope.

In terms of experiencing an MS diagnosis, adolescents often described an initial feeling of surprise, anxiety, and a lack of understanding of their illness. This is consistent with other studies of adolescents after receiving a diagnosis of type 1 diabetes, which patients described as shocking and accompanied by feelings of anger and sadness (Rodham, McCabe, Pilkington & Regan, 2013). It has been noted that during the early stages of coping with such a diagnosis, patients tend to feel helpless and out of control.

In terms of adapting to health care and treatment, as adolescents became informed about MS and MS treatments, they seemed to undergo a process of adaptation and learning to live with the condition. This goes in accordance with other findings (Heaton, 2015; Woodgate & Edwards, 2010), where young people report following and eventually assimilating structured treatment routines into their daily lives with decreasing amounts of stress (Lam, Lee & Shiu, 2014).

Interestingly, when making decisions to cope with MS diagnoses, some adolescents described their experience of chronic illness in positive terms. This coping style is like that of a study of African-American adolescents, which described this strategy as *effective coping*.

Chandra & Batada (2006) indicate that African-American adolescents rely on friends and family members to cope with the stress of their daily lives, and Berg *et al.* (2009) showed that those with type 1 diabetes perceive themselves to have effective coping and have better metabolic control. It has been suggested that, in individuals with diabetes, internal self-efficacy can help patients remain optimistic, and this optimism may be driven by self-esteem, feelings of responsibility, and feelings of control (Heaton, 2015). Adolescents also reported minimizing negative emotions which could be a *passive coping*, maladaptive strategy that includes avoidance behaviors leading to future dysfunction (Brown *et al.*, 2012; Whittemore, Jaser, Guo & Grey, 2010; Woodgate & Edwards, 2010); however, in this study, it seemed that *passive coping* with negative emotions may be part of the adaptive process, since it was often associated with reports of an optimistic attitude.

Decision-making based on the type of coping strategies employed can impact health. There is evidence that the optimal adaptation to chronic disease occurs when an individual is able to distinguish between what he/she can and cannot control (Woodgate & Edwards, 2010). Similarly, there are indications in the literature that disease management has its limits, and that identifying areas where control can be exercised may help with adaptation, suggesting that adolescents with MS should be encouraged to look for opportunities to exercise control in their lives (Lazarus & Folkman, 1984, Whittemore *et al.*, 2010).

Study participants were recruited from a public hospital, limiting generalizability to those already involved in management and treatment programs. The experiences of the adolescents who refused to participate could be different from those that did participate, leading to a possible selection bias and, again, limiting generalizability. In addition, there were more men than women participants. The literature suggests that men and women respond to chronic disease diagnoses differently (Williams, Teasdale, Segal & Soulsby, 2000); however, it was not possible to explore gender differences in this study.

## Conclusion

The use of a qualitative methodology and phenomenological perspective allowed us to gain an initial understanding of adolescents' experiences and adaptive coping strategies after an MS diagnosis. Overall, these results indicate that adolescents receiving an MS diagnosis were able to overcome their initial -often negative- experiences, they were motivated to adhere to management and treatment plans with support from healthcare and educational professionals, and they were able to develop adaptive coping strategies a short time after being diagnosed. Ultimately, a better understanding of the MS epidemic in adolescents is

needed along with improved primary prevention and better treatment options. These findings indicate that, with support, adolescents could adapt to new prevention, management, and treatment strategies.

This study shows that adolescents who overcome their first -often adverse- reaction could find ways of adapting and continuing with their lives. However, the experiences of those adolescents who do not adapt well when diagnosed are unknown. It is important to perform a more comprehensive study of adolescents with MS and with greater disease duration in public hospitals to determine the level of treatment adaptation.

## Acknowledgments

Dr. Onofre-Rodríguez thanks the Consejo Nacional de Ciencia y Tecnología (Conacyt) for the scholarship to pursue a Ph.D., during which this research was conducted. This paper was finalized during the postdoctoral stay at El Colegio de la Frontera Norte (Colef) in 2016. We thank the adolescents who participated in the study.

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