

## Review Article

# Caregivers' sleep of Duchenne Muscular Dystrophy's patients: a short review

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## Abstract

The task of a caregiver might exert several effects upon his/her physical and psychological health. It should be highlight the role of the caregiving mother (CM) of patients with Duchenne Muscular Dystrophy (DMD). DMD is a genetic-character disease with a prevalence of 1 to every 3,500 boys live births and with high mortality rate. The disease's progression significantly compromises the quality of life and mainly the patient's independence, making it indispensable the presence of a caregiver. The overload of physical and emotional work, including nocturnal periods, may interfere with the CM's sleep. CM with a son with DMD demonstrated lower sleep efficiency, higher sleep latency, and reported poor sleep quality. These modifications might negatively interfere with health and quality of life of these CMs. Therefore, the evaluation of sleep pattern and quality in this subjects is most important and essential, being for their own global health, as well as for the patient's well-being. We point out the need for a major interest from the scientific community and health professionals in better understand the impact of chronic diseases on health and quality of life of caregivers and patients..

## Introduction

*"My sleep is light, any little noise will wake me up, he gives a little scream and I am awake, because I have to see what is happening to him"*

Report of a caregiving mother with a son with Duchenne Muscular Dystrophy

The term "caregiver" refers to a person responsible for the intervention, protection and health recuperation of an individual, with formal or informal relationship with the patient [1]. The formal caregiver is the graduated professional who has the knowledge and the specific training, besides receiving a salary for the services rendered. The informal caregiver is the one who possess little or no technical knowledge and works without any salary [1]. Normally, the informal caregivers have been family member, being by their proximity, being by the economically difficulty generated by the employability taxes inherent to formal caregivers. The caregiver becomes responsible for the personal hygiene, feeding, administering medications, locomotion and distractions of the patient, providing unaccountable tasks and responsibilities. According to the National Caregiver Survey, 71% of all caregivers are women between the ages of 41 to 55 years [2]. The figure of a woman deserves to be highlighted as the primary caregiver [3] mainly because of the relationship as spouse, sister, daughter or mother [1]. Among the main reasons for a woman to assume the role of the main caregiver, it should be pointed out the sentiment of a family obligation and the emotional and social relationship with the patient [4,5]. It has also been observed that women demonstrate a higher feeling of altruism and self-sacrifice [6,7].

## Duchenne Muscular Dystrophy

Chronic diseases are clinical conditions with a higher demand for the presence of a caregiver due to the need of a continuous and long-term treatment and permanent care. In chronic diseases with diagnoses on the first years of life, such as neuromuscular diseases, the family exerts a fundamental role upon the care of the diseased child.

Neuromuscular diseases are affections that compromise the motor unit, leading to a generalized muscle atrophy of the superior and/or inferior limbs, oropharyngeal and breathing muscles, making it difficult for the patient to walk, swallow, speak and breathe [8]. Muscular dystrophies are characterized by genetic disease with a progressing degeneration of the muscle tissue [9]. Up to this moment, we have the knowledge of more than 30 forms of muscle dystrophies. The most frequent and severe form is Duchenne Muscular Dystrophy (DMD). The estimate incidence of DMD is of 1 at each 3,500 live male births [10]. In addition to being of hereditary transmission, approximately 1/3 of DMD cases are the result of new mutations without any previous familiar history [10]. These cases are generally the results of a gene mutation, as the gene responsible for DMD has a significant number of base pairs, corresponding to about 1.5% of the X chromosome and, therefore, being highly susceptible to mutations. DMD is a neuromuscular disease of recessive genetic character, intimately linked to the X chromosome. In this disease, the gene localized at the short arm of the X chromosome and at the Xp21 region, suffers a mutation, promoting an alteration or the loss of the protein dystrophin codification [9,11]. As a consequence, there is muscle impairment, leading to a progressive and irreversible loss of muscle contractile function. In DMD, the newborn is apparently normal, perceptible symptoms begin only at childhood. Between 2 and 4 years of age, we can observe the first clinical signs, such as muscle weakness (frequent falls, difficulty in locomotion, running and ladder climbing), hypertrophy of calves, fatigue, Gowers' sign (clinical sign characterized by an "escalation" that the child does with his legs, using

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the hands over his knees and after, on his thighs, to support the weight while standing up) and learning difficulty [12]. Between 7 and 13 years of age, it occurs a loss of ambulation and there is the need for the use of a wheelchair. After this phase, it follows a decline of the pulmonary function [13], and the respiratory failure is the cause of death in about 80% of the patients [14-15]. Survival goes until the third decade of life (about 25 years of age), mainly due to cardiac or respiratory failure [16]. Ventilation with the help of a non-invasive ventilatory support (NIV) minimizes the progression of the ventilatory insufficiency, improving therefore, the quality of life and life expectancy [17].

## The caregiver in Duchenne Muscular Dystrophy

During infancy, the basic care that any child needs, the infant with DMD needs some extra care from their parents. With the progression of the clinical signs, the patient becomes more debilitated and the time spent caring increases exponentially. During the night, due to the movement restriction and NIV adjustments, the patient needs constant care and continuous observation. In general, the patient needs help to put the equipment on and to monitor the equipment during the entire night. The intense individual needs for almost all their daily activities, besides the medical routine ones, such as consults, exams, motor and respiratory physiotherapy, among others. Generally, the informal caregiver of DMD patients has to get away from his/her regular job or other activities to fully dedicate himself/herself to this task. It is usual that the mother takes on the job of the main caregiver of patients with DMD. Studies conducted in Brazil demonstrated that the mother is the main caregiver of children with DMD [18,19]. Data from our group confirm these findings. In a study conducted with 35 children with DMD, all patients had the mother as the main caregiver [20]. Even though the family tries to find alternatives to minimize the impact of the disease, muscular dystrophies might also significantly affect the quality of life of patient itself and his/her family members.

After the second decade of life, DMD get worse, with an increase of hospital admissions, increase in respiratory and nutritional complications and need of intensive care support. During this phase, the caregiving mother (CM) suffers a marked emotional impact due to fear of complications or by the fact of knowing that her son has evolved to a terminal stage. The constant care and the difficulties in accomplishing regular daily tasks, and the major dependency of the sick person, might induce a physical overload and, mainly, a psychological overload to the caregivers [21]. This overload might be manifested by means of several symptoms, such as depression [22-24], fatigue [25,26], sedentary life-style [27], reduction of social activities [27], irritability [27], susceptibility to infections [28], anxiety [24; 29], cardiovascular problems [30], stress [19], and sleep disorders [31-34].

## The sleep of caregiving mothers

Good sleep quality is of extreme importance for the organism's homeostasis, as sleep is a physiological process of high relevance to maintain physical and mental integrity. A reduction of sleep time or quality might trigger several consequences to health, including impairments in immune response [35], sexuality [34,36], and metabolism [37]. Therefore, sleep disorders represent a high health risk associated to several comorbidities [38]. The impact of sleep disorder upon functional capacity, health and well-being, added to the emotional overload that affects the family of a person with DMD, demonstrates the importance of sleep for the CM. With the intensity of a multitude of tasks and to the total dedication to her son, frequently CM underestimate and neglect their own health. The emotional overload

present in the work of a CM indicates the relevance of evaluating the individual perception of sleep quality. Some studies have demonstrated impairment in the caregivers' subjective sleep quality of children with chronic diseases [31,32]. In caregivers of children with asthma, it was noted a higher number of awakenings and reports of light sleep due to the preoccupation and the vigilance of their sons [39]. In another study conducted in CM of children with cerebral palsy, it was observed that 92% of these mothers reported poor sleep quality, and this was associated with the habit to share the bed with their sons [40]. The main reason for bed sharing was the need of constant care with the son, due to his/her immobility. CM of children with acute lymphoblastic leukemia demonstrated insomnia, a symptom that is correlated with the stress and affliction [41]. In the same study, although not statistically significant, CM had several awakenings and sleep fragmentation, evaluated by sleep diary and actigraphy. Our group observed that CM of children with DMD demonstrated worse sleep quality than the mothers of healthy sons. CM reported worse subjective sleep quality and higher sleep latency [42].

Even with sleep deprivation and constant awakenings due to the night overload of caring for the patient with DMD, CM did not show excessive diurnal sleepiness (EDS), evaluated by the Epworth Sleepiness Scale [20]. There is controversy in the literature as to the existence of EDS in caregivers, once some authors showed the presence of EDS [39,43], while others, did not [44]. Even among the caregivers of healthy children with ages around 10 years, the percentage of EDS was low. According to The National Sleep Foundation [45], only about 7% of caregivers reported EDS almost every day, while 19% described it only some days of the week. According to this study, the caregivers that reported EDS in, at least, some days of the week, were those who slept less than 6.4 hours per night, while the ones who did not demonstrated EDS, slept an average of 6.9 hours per night. Explanations for the presence of EDS in this population could be associated to the depressive symptoms or even the fact that the caregiver was single and the only person responsible for the son [39]. In the other hand, the lack of EDS might be due to the fact that the caregiver had the opportunity to take a nap during the day, once the caregiver did not work someplace else besides this family duty [44]. This divergence between the studies might be explained by the load of care employed for each disease, as well as the periods during the day with more need for care. Although in DMD, the CM shows a high load of nocturnal work, the daily routine is intense, which might mask the underlying sleepiness and did not allow them to nap during the day.

A factor that might influence sleep quality of CM is the prognostic of the disease and the treatment that her son is exposed to. In DMD, there are three important aspects to highlight: the diagnostic, the insertion of a wheelchair and the beginning of the use of NIV. Although NIV is associated with the improvement of the sleep disorders and life expectancy of DMD's patients [46], there are a few risks associated with its use. Possible defects in equipment's function and the disconnection or energy failure are some of the risks that might cause the NIV-dependent patient's death [47,48]. For this reason, the initial phase of NIV use may be a period of great concern for the CM and, consequently, compromising sleep. The use of NIV [32] and its time of use are inversely proportional to the CM's quality of sleep [42]. CM that showed worse subjective sleep quality was the ones whose child used NIV for the shortest time (average of 25 months). Better sleep quality was associated with a longer time of NIV use, approximately, 63 months [42]. It should be pointed out that the percentage of use and the average of NIV's daily use did not influence CM's sleep quality

[42]. The CM's sons with DMD with good sleep quality used NIV at an average of 10.1 hours/day and with an adherence of approximately 96.2% to NIV. In CM with poor sleep quality, their children with DMD used NIV in an average of 12.3 hours/day and with an adherence of 98.3% to NIV. Time of use since initiation of NIV was the main factor related with sleep impairments in CM. This finding might be related to the CM's psychosocial adjustment. With the passing of time, CM and the patient itself adapt to the use of NIV and, consequently, sleep improves for both of them. Interestingly, it has also been observed the increase in sleep latency, reduction of total time of sleep, and poor quality of sleep in CM with children with a chronic disease and the use of NIV in comparison with the control group [32]. Similarly, to our findings, Boman *et al.* [49] evaluated the sleep of caregivers of children with cancer and observed higher frequency of sleep disorders. Furthermore, caregivers with poor sleep quality were the ones with lesser time with the disease's diagnostics. In addition to the factor time, stress [50] and bed sharing [40] are also related to caregiver's sleep quality. Sleep problems in caregivers were associated with maternal depression, fatigue, anxiety, impairment of diurnal functioning, and worst perception of sleep quality [31,32,50,51].

It is estimated that 2/3 of caregivers will develop sleep disorder during his/her career as caregiver [52], indicating that sleep is one of the main aspects affected in this population. Studies have demonstrated a high frequency of sleep disorders in caregivers of adult [53,54] and pediatric patients [32,55]. The main caregivers' sleep problems are the reduction of total sleep time, increased sleep latency, and sleep fragmentation [54]. The sleep problems in caregivers of cancer patients generally persist even after hospitalization and the death of the patient [56,57]. It has been observed that, even after 5 years of the patient's death, the caregiver could still have insomnia symptoms [58], and this sleep problem can difficult his process of facing the post-mortem period. Evaluating the sleep pattern of DMD caregivers, our group also found mothers who demonstrated reduction in sleep efficiency and significant increase in sleep latency, corroborating the literature [20]. At polysomnography (PSG), we observed an increase in sleep latency in CM ( $22.5 \pm 2.9$  minutes) when compared to control group ( $12.6 \pm 2.9$  minutes). PSG studies confirmed the subjective findings evaluated by the Pittsburg questionnaire. Similar to our data, Rowe *et al.* [54] found an increase in sleep latency in caregivers of patients with dementia, when compared with non-caregivers. The increase in sleep latency might be related to psychiatric problems [59] and, chiefly, to preoccupation with the son. Patients with depression could present an increase in sleep latency, higher number of awakenings during sleep, and early awakening, which might compromise sleep efficiency [60]. Another aspect identified in CM's sleep was the increase in the percentage of N3 sleep (24.9%) in relation to the control group (20.7%) [20]. It has been already described that the slow wave sleep is related with homeostasis regulation and the pressure to initiate sleep [61]. Repeated periods of sleep deprivation might increase in approximately 20% the slow wave sleep, and this increase is usually normalized after sleep recovery [62]. Thus, the increase in N3 stage sleep might be caused by the homeostatic pressure for sleep in consequence of a chronic sleep deprivation observed in the CM sample with marked nocturnal activity. It should be pointed out that CM do not have the possibility of long periods of sleep, or, they are still submitted to a constant sleep fragmentation due to their task as caregivers during the night. The evaluation of sleep diary data demonstrates that the CM of patients with DMD reported a higher number of awakenings and sleep fragmentation [20]. Data from CM of children with chronic diseases showed that this population sleep an average of 4.5 hours per night

and reported being awake for about 3 hours to take care of their sons during the night period [31]. In broncopulmonary dysplasia, the CMs reported to sleep an average of 5.8 hours per night [55]. The variation on the total time of sleep among the caregivers can be dependent of the type and severity of the disease, besides individual differences in sleep needs. Despite this variation, sleep deprivation seems to be common in caregivers, leading to several physical and mental health's impairments.

## Future perspectives

With the advances in medical area, facility in access treatments and the increase in life expectancy, there is a change in population health profile. The increase in the prevalence of chronic degenerative diseases and their complications, results in a major need for the help of a caregiver. In general, the women are the ones to take care of this task, mainly when the patient is a child. Although several studies had documented the mechanisms and the clinical manifestations of muscular dystrophies, few studies investigated the consequences of the disease, in particular with DMD, to CM health and quality of life. We expect that further studies will be conducted to comprehend the biopsychosocial impact of the caregiver task, advising of the importance of evaluating CM's sleep in research area and in the clinical practice. In this sense, strategies to improve health and promote the well-being of CM can be elaborated, increasing the caregiver quality of life and, indirectly, of their patients.

## Conclusions

The presence of chronic conditions such as DMD interferes in the quality of life of the patient itself and their relatives. The main caregiver, who in DMD is usually the mother, generally suffers the major emotional and physical impact. Among the several health problems already reported in literature, sleep impairments have been investigated as an important factor over the reduction of the quality of life in this population. CM with sons with DMD showed lower sleep efficiency, higher sleep latency and report worse sleep quality. These modifications might negatively interfere on the CM's health. Therefore, the evaluation of CM's sleep quality is indispensable and essential, being by its own global health, or being for the patient's health and well-being. With all the clinically recognized support given to the son with DMD, it is essential that the multiprofessional health team offer a proper attention, orientation and treatment to CM.

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