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Factors influencing adherence to continuous positive airway pressure devices in individuals with spinal cord injury and sleep apnea: results of a qualitative study

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Abstract

Background. In individuals with spinal cord injury (SCI) and sleep apnea (SA), adherence to continuous positive airway pressure (CPAP) therapy seems unsatisfactory despite technical and educational support implemented when starting treatment.

Objective. We aimed to design comprehensive model of adherence to CPAP therapy in individuals with SCI and SA.

Methods. This was a prospective qualitative study based on semi-directed interviews and using the grounded theory as an analytic method. The theoretical framework was the social cognitive theory of Bandura. Participants were recruited from an SCI referral centre. Individuals with SCI using or having used a CPAP device for SA were included. Data were collected by semi-directed interviews on the experience of individuals with SCI regarding SA and being fitted with a CPAP device and were coded and organized into categories of experience and category relationships.

Results. Among the 17 individuals included; 9 had tetraplegia; the median age was 62 (Q1–Q3 47–66) years and median time since injury was 16 (Q1–Q3 1.75–21) years. Four categories of data were identified: 1) from symptoms to validation of SA diagnosis, 2) CPAP device fitting process, 3) representations of SA, and 4) level of adherence to the treatment. In addition to the factors already observed in the general population, the proposed model identified specific adherence factors in individuals with SCI, such as physical and relational dependence on a third party, increased daily care burden and increased presence of medical devices in the daily environment.

Conclusion. SA and its management present certain specificities in individuals with SCI that the physician must take into account to optimize therapeutic proposals, follow-up modalities and device adherence.

Introduction

Sleep apnea (SA) is a sleep disorder defined by cessation (apnea) or significant decrease (hypopnea) in airflow in the presence of breathing efforts. It is a public health issue concerning 4% of men and 2% of women in the general population[1,2]. In individuals with spinal cord injury (SCI), the prevalence of SA is 2 to 5 times higher than in the general population [3,4] starting at year 1 post-injury [5]. In addition to the SA classical risk factors — male, age, overweight, neck circumference [6] — some specific SCI-related risk factors could be involved [7] — level of injury [8,9] intrathecal baclofen boluses [10] or positioning [11] — but results of studies diverge[12,13]. The impact of SA on drowsiness and cognitive functions is well known in individuals with SCI [11,12,14–16]. The cardiovascular impact of SA was evidenced in the general population but was not specifically studied in individuals with SCI; however, cardiovascular pathologies are the second cause of mortality in this population [17].

Diagnostic criteria and therapeutic indications are the same as in the general population. The gold-standard treatment is nocturnal continuous positive airway pressure (CPAP) ventilation. Adherence to the device is measured by the mean number of hours used per night. The American Thoracic Society defines the adherence objective as 4 hr/night in 70% of the nights recorded [6]. Below this threshold, the clinical efficacy disappears or is insufficient [18]. To prevent the cardiovascular consequences of SA, a minimum use of 4 hr/night seems necessary [19] but is debated [20].

In the general population, 65% to 85% of patients retain adherence to the device at 1 year [6]. In individuals with SCI, CPAP therapy adherence seems less satisfactory, with reported adherence of 27% to 74% depending on the study, despite the technical and educational support implemented when starting the treatment [8,14,21–23].

Burns et al. [21] studied 23 patients with tetraplegia who were fitted with a CPAP device for SA. Individuals with a level of injury above or equal to C5 were significantly less compliant than those with a level of injury at C6 or below. In a second study, Burns et al. [16] evaluated via a questionnaire the determinants of CPAP treatment acceptance for SA in 40 individuals with SCI. The reasons most frequently reported for giving up the CPAP device were the inability to fall asleep (67%), lack of symptom improvement (25%), and belief that the treatment was useless (8%). The main limitations of this study were the exploration of treatment adherence factors via a directed questionnaire, not allowing the exploration of the adherence phenomenon without bias, and the design of the questionnaire not based on an underlying observance theoretical model.

A qualitative research approach based on a theoretical model could explore the treatment compliance phenomenon without bias. We chose the social cognitive theory of Bandura [24] that is widely used in the literature to analyze health-related behaviors[25–27], mainly in studies of adherence to CPAP as a device for SA in the general population [28]. The core determinants of the model include knowledge, perceived self-efficacy, outcome expectations, health goals, and facilitators/barriers. Self-efficacy is the belief of patients in their ability to exercise control over personal health habits. Bandura suggested that the application of social cognitive theory must be situated in context, recognizing that "human behavior is socially situated, richly contextualized, and conditionally expressed".

The objectives of this study were to evaluate the factors that affect treatment adherence to a CPAP device for SA in individuals with SCI and determine any factors that the prescribing physician should take into account to optimize care and monitoring in this SCI population.

Methods

Study design

This was a qualitative cross-sectional study. Semi-structured interviews were conducted from August 2016 to April 2017 with use of a standardized interview guide. The study protocol was approved by the Ethical Committee Sud Mediterranée 1 (reference no. RO-2016-10) and adhered to the COnsolidated criteria for REporting Qualitative research (COREQ)[29]. Written informed consent was obtained from all participants before inclusion.

Participants

To be included in the study, individuals with SCI had to meet the following criteria: stable neurological state for at least 6 months, age > 18 years, and using or having used a CPAP device for SA. Individuals with a tracheotomy were excluded. Participants were recruited from an SCI centre during their regular follow-up consultation or during a hospitalization. The study was proposed by their attending physician. Purposive sampling with sex, age and neurological level as participant characteristics was used to obtain maximum variation in these characteristics. After receiving clear and reliable information and signing the consent form, the individual was included in the study.

Data collection

The participant was interviewed by the main investigator, a medical doctor trained in active listening techniques, during the standardized and recorded semi-directed interview. The investigator was blinded to the adherence status of the person. Adherence declared by the participant was named “self-reported adherence”, and compliance measured by the CPAP device was named “objective adherence”. An interview guide was specifically designed for the study by a multidisciplinary expert committee (CB, AL, FCG, AG) on the basis of the socio-cognitive theory (Fig. 1) and previous publications in this field (Appendix 1). The interview guide was not amended during the study. It included open-ended questions, and the objective was to obtain as much information as possible from the participant without guiding or influencing the feedback. The interview lasted for 30 min, on average. It took place in the outpatient centre or in the hospitalization unit, in a quiet room. Only the participant and the investigator were present. Each interview was recorded by using a digital recorder. The investigator also took notes during and after the interview in order to refine the elements related to the context, such as non-verbal reactions or ideas that came up during the interview. These notes were kept as a memo. Each interview was transcribed verbatim by a third-party supplier and the corresponding memo was attached by the investigator. The verbatim transcriptions and corresponding memos were stored in R package for Qualitative Data Analysis (RQDA; RStudio, v0.2-8, 2016). The interviews continued up to data saturation (i.e., until there was no further need to sample more data for analysis).

Data analysis

We used the grounded theory to structure our analytic approach [30]. The work group (CB, ALB, AG, AS, MG) analyzed each verbatim transcription to categorize in codes the relevant elements of the interview, with blinding to the compliant or non-compliant status of the participant. These codes were treated with the RQDA software also used for data storage. The codification was considered at saturation when no new code appeared after a full comprehensive interview. The work group organized these codes into categories, each category representing a component of the global phenomenon. Categories were precisely described and defined. Also, relationships between these categories (e.g., causal, dependence) were defined. The comprehensive adherence model was built by using the different categories and the relationships between them. To verify the validity of the models, verbatims that were not coded were studied to check whether the codes and categories found were present in the comprehensive adherence model.

Results

Code saturation was obtained after the inclusion of 17 male individuals with SCI; 9 had tetraplegia; the median age was 62 (Q1–Q3 47–66) years and median time since injury was 16 (Q1–Q3 1.75–21) years (characteristics are in the Table). Participants were all fitted with a CPAP device at the time of inclusion. No participant had known syringomyelia or spinal complications. At the end of the study, 2 non-compliant subjects had given up the CPAP device.

With the 61 codes retained, we formulated 8 themes grouped into 4 categories described below (Fig. 2, Appendix 2): 1) from symptoms to validation of SA diagnosis, 2) CPAP device fitting process, 3) representations of SA, and 4) level of adherence to the treatment.

Category 1: From symptoms to SA diagnosis

What led to the diagnosis?

This theme groups the different elements from awareness of sleep disorders to SA diagnosis. The experience of the symptoms by the participant and/or family members was a determining element of the process. *"I was taking naps; they weren't even naps but lasted 2 to 3 hours. It is disruptive because at one point you end up not doing anything at all." Participant 14, paraplegic*

The elements can trigger anxiety or deteriorate the sleep quality of the individual and consequently the partner's sleep. An important gap exists between the perception of the symptoms, from the moment they became noticeable to family members and the first medical consultation. *"She (my wife) suggested I see a cardiologist and get tested, because I wouldn't do anything." Participant 11, tetraplegic*

Sleep recordings evidence of SA

This theme describes the importance for certain participants to have the diagnosis validated by an additional examination. The participant often experienced the number of apneas per hour or their duration as elements of disease severity. *"This is when the pulmonologist opened my eyes by telling me 'you should be careful because you have a high number of episodes' because at times I had 60, 70 apneas per night, in fact." Participant 10, tetraplegic*

<u>Catégory 2: CPAP device fitting process</u>

Setting up the CPAP device

At the time of the CPAP device fitting, 2 elements seemed determinant: experience regarding the device prescription and first time wearing the device. In our study, the prescription was often felt imposed by the physician, too quickly after diagnosis. *"They put me on the device directly. They didn't ask." Participant 4, paraplegic.*

The first night wearing the device could be a positive experience that could promote adherence despite major constraints perceived. *"Air was flowing full force, it made me breathe better. It was good and I had a very good night." Participant 17, tetraplegic*

A first negative experience could completely compromise the treatment. For most compliant participants, an adaptation period was necessary, to get used to sleeping with the device and to tailor the CPAP equipment to each participant. The adaptation of the CPAP device concerned the equipment–patient interface, adapting the material to patients' disabilities and their environment to improve the individual's independence and thus promote treatment adherence. Suppliers were also perceived as available and efficient in how they provide support to patients.

Perceived benefits of the CPAP device

The benefits were mainly physical (daytime sleep and fatigue), but other participants reported benefits on a social and relational level.*"I was less tired, I was rested in fact; it makes a big difference really. You know when you talk to someone and you fall asleep, so as soon as this no longer happens it means the situation has progressed, so it is very positive this machine." Participant 5, tetraplegic*

Some participants, compliant or non-compliant, reported the absence of perceived benefits in their daily lives.

Perceived constraints

Device-related discomfort was most often mentioned. It could be due to the patient–device interface, difficulties falling asleep with the device, noise, nighttime manipulations of the device, etc. *"I wake up when the device starts and I can't follow the forced airflow. At one point I feel oppressed and this is when I wake up." Participant 16, tetraplegic.* It could concern the individual wearing the device or the partner sharing the bed. It could be a temporary discomfort or remain unresolved despite solutions proposed. The cosmetic impact was also brought up, without seemingly having an impact on treatment adherence. It affected the self-image and relationship with the partner.

The annual follow-up consultation with the specialist physician could be perceived as an administrative constraint. For most individuals, SA was an additional medical issue, adding up to the numerous medical interventions. Finally, the device could be a barrier to social participation. It was included in the long list of medical equipment and technical aids installed in patients' home and taken with them when going outside. *"It is one more stuff to take with us when we go somewhere, an extra piece of luggage." Participant 16, tetraplegic.* There was also a stigmatization of the living environment shifting into a care environment.

Category 3: Representations of sleep apnea

This is the process of constructing the representations of SA, which will condition the perceived severity of SA.

Access to information

The privileged sources of information were other people with CPAP therapy. These individuals held information considered reliable because it is based on experience, generally known as the "expert patient" concept [31]. *"I tell you, after the discussion I had with a friend you get squared away quickly. You say to yourself 'yes, I get it', the doctor told me but I didn't really do anything, but here when someone gives you some real information it makes you react." Participant 5, tetraplegic.* Individuals sought information from the supplier and people they knew who worked in the medical field. The physician giving the SA diagnosis was rarely identified as a reliable source of information.

"Perceived level of severity"

The perceived severity of SA could vary greatly. Some participants believed it was a benign pathology. *"You view the snoring as something normal that happens with age" Participant 17, tetraplegic*

Conversely, most participants considered SA as a severe pathology, characterized by airflow cessation that could be fatal, a chronic pathology that cannot be cured and a source of cardiovascular risk. *"I should wake up, like a safety mechanism, I don't know, to tell myself 'hey you're dying now.' " Participant 3, tetraplegic*

<u>*Category 4: Level of adherence*</u>

Adherence is not binary but rather presents as a continuum. Dependence, similar to an addiction, could sometimes be expressed in relation to the device. For some, the device was part of their daily routine. Some even promoted screening for SA among their friends and social network, which is an indirect but interesting indicator of treatment adherence. *"Now I am the first one now, the first preacher to tell people to consult when I hear symptoms such as this one." Participant 17, tetraplegic*

The adherence could be insufficient, despite daily use, because patients have to make a choice between the discomfort of the device and the quality of their sleep.

Adherence also changes over time. A patient who has been compliant for several years could rethink the relevance of the device or even give up using the CPAP device during an acute pathological episode when SA became secondary. Conversely, a non-compliant patient could become compliant after a triggering factor (e.g., testimonial of a friend or family member using the device, encouragements from loved ones, worsening of the symptoms). Family members and friends could promote adherence (helping putting on the device, encouragements) or be a barrier (device is disruptive for the partner's sleep quality). *"Sometimes I would fall asleep and she would tell me 'hey put your mask on,' so I did as told and it became a habit really." Participant 8, paraplegic*

Discussion

This study proposed a qualitative approach for adherence to CPAP therapy in individuals with SCI presenting SA. To our knowledge, this is the first study of this type in this specific population.

In the general population, the development of management of SA quickly identified the issue of treatment adherence to the CPAP device. The first studies of the subject focused on the constraints related to the device itself (e.g., discomfort of the mask, dry mouth, and ventilation modes)[32], which led to the development of technical or technological solutions (e.g., diversification of the interfaces, humidifiers, adjustment modalities of the CPAP equipment), with initially an impact on adherence, which progressed up to 65% at the beginning of the millennium but has not really increased since[33]. For this reason, increasing studies have based their work on multifactor models developed in health psychology (e.g., Health Belief Model, social cognitive theory of Bandura) to identify other factors involved in treatment adherence [28,34–37]. For example, Sawyer et al. [28] performed a qualitative study of 15 individuals with SA but without SCI that was based on the social cognitive theory of Bandura during the initial treatment phase. A great number of adherence determinants identified were identical to those we found: the perceived severity of the pathology, the importance of the first fitting experiences, perceived benefits of the CPAP treatment (sleep quality, social impact), the benefit/risk ratio, the role of family members and friends, self-efficacy emerging from discussions with patients underlying the need for an adaptation period and the implementation of actions allowing to solve barriers related to starting the therapy and wearing the device. Finding similar adherence factors in the SCI population is not surprising because factors underlying the adherence process are generally described in theoretical models such as the socio-cognitive approach, but the weight of these several factors might differ because of the SCI specificity. For example, in the general population, the weight of the different categories in Bandura's adherence model reported for SA therapy was evaluated in several studies. The classical risk factors (i.e., demographic variables, apnea severity, side effects) explained only 4% to 25% of the adherence variation [38–40]. The determinants of the social cognitive theory could elicit 40% of the variation when they are assessed at 1 month after the beginning of the treatment[36]; furthermore, they can predict long-term adherence [35].

The results of our study highlight the specificity of the SCI population in light of the constraints perceived by participants, which are related to not just physical dependence, as suggested by the few studies completed [21]. The issue of dependence related to installing the device can concern individuals with tetraplegia without family or professional caregivers, but it seems quickly resolved and largely secondary in light of the other constraints. The issue is mostly based at a relationship level, especially with the life partner. The role of the bed partner in CPAP adherence has been recognized in the general population [41,42]. The partner of the individual with SCI is already involved in many activities of daily living, nursing care [43] and prevention of secondary complications [44]. The apparition of these added constraints within the couple changes the nature of the relationship and can increase the risk of separation or partner's exhaustion [45–47].

The additional medical burden related to the SA diagnosis seems more important in individuals with SCI, when this pathology is far from the core of their preoccupations. In a qualitative study, Rubinelli et al. [48] interviewed 1762 individuals with SCI on their main perceived health issues since their injury related to the International Classification of Functioning, Disability and Health categories. Sleep disorders, including SA, were ranked 63rd and mentioned by only 1.25% of the participants.

Several recommendations can be made for physicians in light of our study results. The patient must be informed of the SA pathology at the time of SA diagnosis and during the care management. This information is designed to help the patient understand SA and the symptoms experienced and even be aware of the negative impact of SA on their quality of life. Knowledge of the consequences of SA on one's health can also help the patient evaluate the severity of the pathology to determine the appropriate actions to be implemented. The prescribing physician must be more involved at the beginning of the treatment, when the device is being fitted. The first weeks seem determinant in the adherence process. This support from prescribing physicians has several objectives, to help the individual identify early on the benefits of the device and to reveal the inconvenient material, technical or psychological constraints related to the device in order to solve them quickly. If the patient lives with a partner, the partner should be involved early on in consultations and the device fitting process. Partners have their own representations of apnea and the device. They can be barriers to treatment adherence but also facilitators on whom the physician can rely on. Finally, in our study, the information based on experience (i.e., from other patients with SA undergoing CPAP therapy) was considered more reliable than the medical and technical information. This information can influence the representations of the patient related to SA and the device. The influence of a support group in which patients (beginners and experienced) could exchange on adherence could be investigated. Future research could focus on a quantitative approach, by evaluating the weight of these different categories in the adherence process and by proposing an adherence scale to screen people with SCI at risk of giving up the device.

Limitations

Our study has several limitations. First, we chose not to include individuals with a Bilevel Positive Airway Pressure (BiPAP) device because it can be an inclusion bias, selecting more severe clinical situations: BiPAP is generally indicated for severe respiratory insufficiency with hypercapnia and in second intention in SA. Second, recruitment involved only one centre, which could constitute a recruitment bias, not representative of the CPAP therapies in this population. However, only 6 of the 17 participants were fitted for the CPAP device in our centre. A second implied recruitment bias concerns the adherence profile of the participants. Even though the proportion of compliant individuals matched the literature, we were not able to include individuals who gave up the CPAP device. This bias in the representation of the sample is lessened by the fact that 2 participants, qualified as non-compliant, definitely gave up the device in the months following the study. Finally, an evaluation of sleep quality and depression would have been interesting to refine the interpretation of the results. The last limitation is the lack of analysis regarding the mechanism of SA (i.e., central or obstructive). To date, we are not able to exclude a potential effect of the SA mechanism on CPAP adherence, and further studies should take this into account.

In summary, this study highlighted that, in addition factors of adherence to a CPAP device similar to those identified in the general population, certain determinants are specific to individuals with SCI: dependence on a third party for putting on the device and relationship implications, increased care burden and additional medical equipment at home, which are already issues in this population. These additional factors can explain the low rate of CPAP adherence in this population. Personalized support and follow-up, taking into account these elements, should improve adherence in this population.

Conflict of interest. None declared.

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Legends

Figure 1. Social cognitive model of Bandura.

Figure 2. Comprehensive model of adherence to continuous positive airway pressure (CPAP) treatment in a spinal cord injury population with sleep apnea (SA).

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Figure 1:

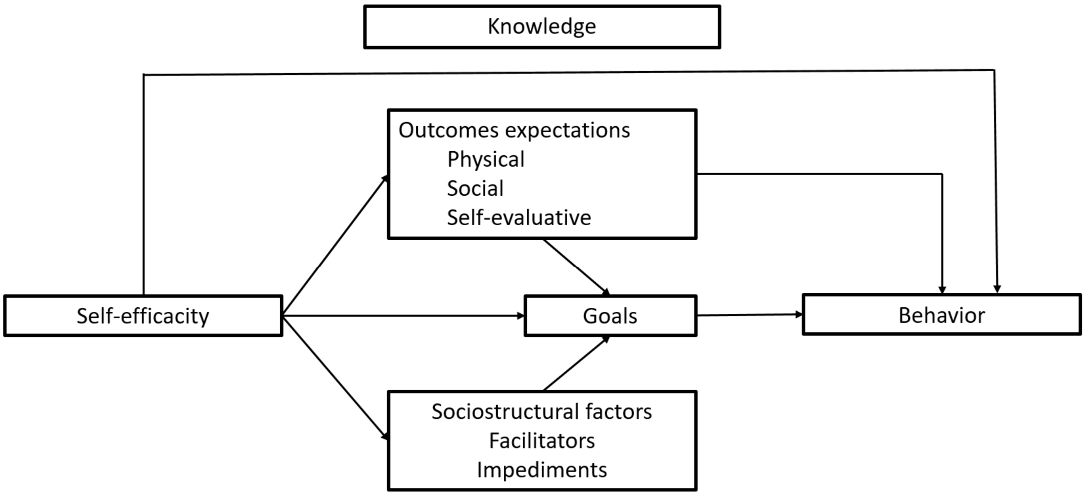
Knowledge
Outcomes expectations
Physical
Social
Self-evaluative
Self-efficacity
Goals
Behavior
Sociostructural factors
Facilitators
Impediments

Figure 2:

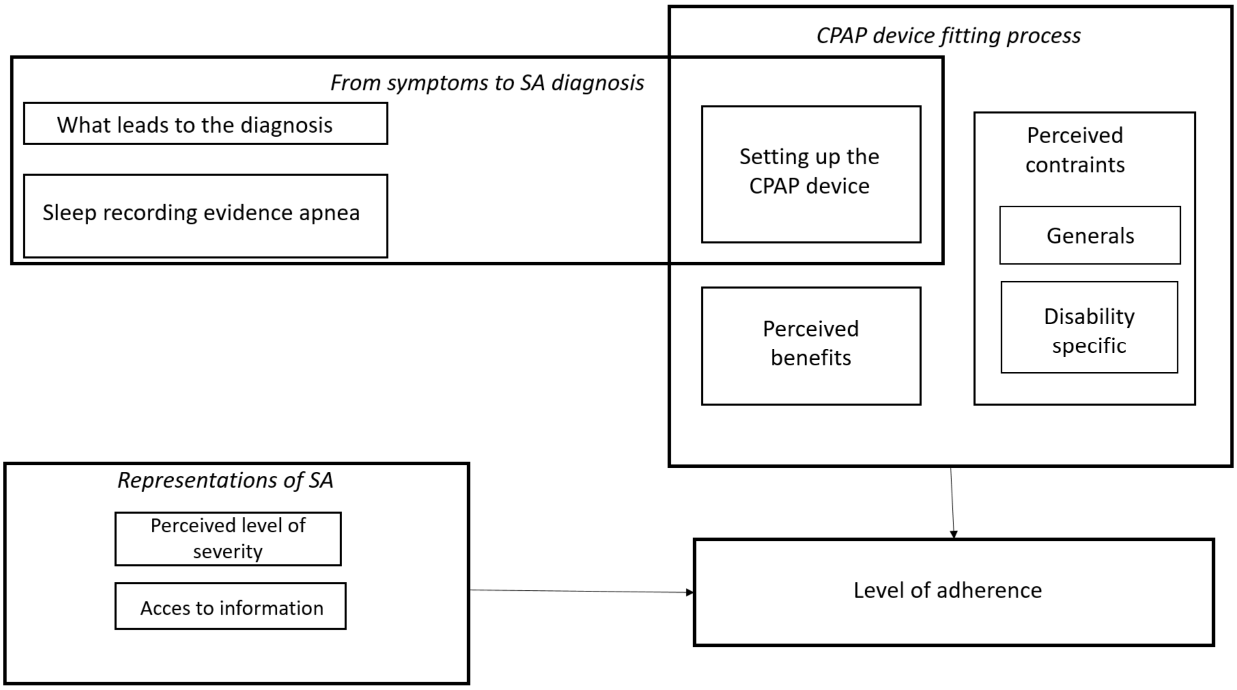
CPAP device fitting process
From symptoms to SA diagnosis
What leads to the diagnosis
Sleep recording evidence apnea
Setting up the CPAP device
Perceived contraints
Generals
Disability specific
Perceived benefits
Representations of SA
Perceived level of severity
Acces to information
Level of adherence

Table. Characteristics of participants with spinal cord injury and sleep apnea with continuous positive airway pressure treatment (n=17).

Sociodemographics	
Age (years), median (Q1–Q3)	62 (47–66)
Sex	
Male	17 (100)
BMI, kg/m^2, median (Q1–Q3)	27 (25–28)
With a partner	10 (58)
Human help	
Nurse visits	5 (29)
Professional caregiver	2 (12)
Nurse visits + professional caregiver	2 (12)
No human help	4 (23)
Has not been home since the injury	4 (23)
Spinal cord injury	
Time since injury (months), median (Q1–Q3)	192 (21–252)
Etiology of the injury	
Traumatic	13 (76)
Medical	4 (24)
Level of injury	
Cervical	9 (53)
Thoracic	8 (47)
AIS grade	
A	10 (59)
B	3 (18)
C	4 (23)
ADL dependence, mean (SD)	
SCIM (/100)	25.9 (13)
FIM (/126)	61.8 (16)
CPAP therapy	
Therapy duration (months), median (Q1–Q3)	35.5 (5-48)
Adherence	
Self-reported adherence (hours/night), mean (SD)	6.1 (2.8)
Objective adherence (hours/night), mean (SD)	5.5 (2.9)
Self-reported compliant status	12 (70)
Objective compliant status	12 (70)

Data are n (%) unless indicated.

AIS, American Spinal Cord Injury Association Impairment Scale, ADL, activities of daily living, SCIM, Spinal Cord Independence Measure, FIM, Functional Independence Measure