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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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21

Abstract

23 **Background.** In individuals with spinal cord injury (SCI) and sleep apnea (SA), adherence to
24 continuous positive airway pressure (CPAP) therapy seems unsatisfactory despite technical and

25 educational support implemented when starting treatment.

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

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

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

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

44

45 **Introduction**

46 Sleep apnea (SA) is a sleep disorder defined by cessation (apnea) or significant decrease
47 (hypopnea) in airflow in the presence of breathing efforts. It is a public health issue concerning 4%
48 of men and 2% of women in the general population[1,2]. In individuals with spinal cord injury
49 (SCI), the prevalence of SA is 2 to 5 times higher than in the general population [3,4] starting at
50 year 1 post-injury [5]. In addition to the SA classical risk factors — male, age, overweight, neck

51 circumference [6] — some specific SCI-related risk factors could be involved [7] — level of injury
52 [8,9] intrathecal baclofen boluses [10] or positioning [11] — but results of studies diverge[12,13].
53 The impact of SA on drowsiness and cognitive functions is well known in individuals with SCI
54 [11,12,14–16]. The cardiovascular impact of SA was evidenced in the general population but was
55 not specifically studied in individuals with SCI; however, cardiovascular pathologies are the second
56 cause of mortality in this population [17].

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

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

68 Burns et al. [21] studied 23 patients with tetraplegia who were fitted with a CPAP device for
69 SA. Individuals with a level of injury above or equal to C5 were significantly less compliant than
70 those with a level of injury at C6 or below. In a second study, Burns et al. [16] evaluated via a
71 questionnaire the determinants of CPAP treatment acceptance for SA in 40 individuals with SCI.
72 The reasons most frequently reported for giving up the CPAP device were the inability to fall asleep
73 (67%), lack of symptom improvement (25%), and belief that the treatment was useless (8%). The
74 main limitations of this study were the exploration of treatment adherence factors via a directed
75 questionnaire, not allowing the exploration of the adherence phenomenon without bias, and the
76 design of the questionnaire not based on an underlying observance theoretical model.

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

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

89

90 **Methods**

91 *Study design*

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

97

98 *Participants*

99 To be included in the study, individuals with SCI had to meet the following criteria: stable
100 neurological state for at least 6 months, age > 18 years, and using or having used a CPAP device for
101 SA. Individuals with a tracheotomy were excluded. Participants were recruited from an SCI centre
102 during their regular follow-up consultation or during a hospitalization. The study was proposed by

103 their attending physician. Purposive sampling with sex, age and neurological level as participant
104 characteristics was used to obtain maximum variation in these characteristics. After receiving clear
105 and reliable information and signing the consent form, the individual was included in the study.

106

107 ***Data collection***

108 The participant was interviewed by the main investigator, a medical doctor trained in active
109 listening techniques, during the standardized and recorded semi-directed interview. The investigator
110 was blinded to the adherence status of the person. Adherence declared by the participant was named
111 “self-reported adherence”, and compliance measured by the CPAP device was named “objective
112 adherence”. An interview guide was specifically designed for the study by a multidisciplinary
113 expert committee (CB, AL, FCG, AG) on the basis of the socio-cognitive theory (Fig. 1) and
114 previous publications in this field (Appendix 1). The interview guide was not amended during the
115 study. It included open-ended questions, and the objective was to obtain as much information as
116 possible from the participant without guiding or influencing the feedback. The interview lasted for
117 30 min, on average. It took place in the outpatient centre or in the hospitalization unit, in a quiet
118 room. Only the participant and the investigator were present. Each interview was recorded by using
119 a digital recorder. The investigator also took notes during and after the interview in order to refine
120 the elements related to the context, such as non-verbal reactions or ideas that came up during the
121 interview. These notes were kept as a memo. Each interview was transcribed verbatim by a third-
122 party supplier and the corresponding memo was attached by the investigator. The verbatim
123 transcriptions and corresponding memos were stored in R package for Qualitative Data Analysis
124 (RQDA; RStudio, v0.2-8, 2016). The interviews continued up to data saturation (i.e., until there was
125 no further need to sample more data for analysis).

126

127 ***Data analysis***

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

139

140 **Results**

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

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

149

150 Category 1: From symptoms to SA diagnosis

151 *What led to the diagnosis?*

152 This theme groups the different elements from awareness of sleep disorders to SA diagnosis. The

153 experience of the symptoms by the participant and/or family members was a determining element of
154 the process. *“I was taking naps; they weren’t even naps but lasted 2 to 3 hours. It is disruptive
155 because at one point you end up not doing anything at all.” Participant 14, paraplegic*

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

161

162 *Sleep recordings evidence of SA*

163 This theme describes the importance for certain participants to have the diagnosis validated by an
164 additional examination. The participant often experienced the number of apneas per hour or their
165 duration as elements of disease severity. *“This is when the pulmonologist opened my eyes by telling
166 me ‘you should be careful because you have a high number of episodes’ because at times I had 60,
167 70 apneas per night, in fact.” Participant 10, tetraplegic*

168

169 *Category 2: CPAP device fitting process*

170 *Setting up the CPAP device*

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

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

178 A first negative experience could completely compromise the treatment. For most compliant

179 participants, an adaptation period was necessary, to get used to sleeping with the device and to tailor
180 the CPAP equipment to each participant. The adaptation of the CPAP device concerned the
181 equipment–patient interface, adapting the material to patients’ disabilities and their environment to
182 improve the individual’s independence and thus promote treatment adherence. Suppliers were also
183 perceived as available and efficient in how they provide support to patients.

184

185 *Perceived benefits of the CPAP device*

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

190 *Participant 5, tetraplegic*

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

193

194 *Perceived constraints*

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

203 The annual follow-up consultation with the specialist physician could be perceived as an
204 administrative constraint. For most individuals, SA was an additional medical issue, adding up to

205 the numerous medical interventions. Finally, the device could be a barrier to social participation. It
206 was included in the long list of medical equipment and technical aids installed in patients' home and
207 taken with them when going outside. *"It is one more stuff to take with us when we go somewhere,*
208 *an extra piece of luggage."* Participant 16, tetraplegic. There was also a stigmatization of the living
209 environment shifting into a care environment.

210

211 Category 3: Representations of sleep apnea

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

214

215 *Access to information*

216 The privileged sources of information were other people with CPAP therapy. These individuals held
217 information considered reliable because it is based on experience, generally known as the "expert
218 patient" concept [31]. *"I tell you, after the discussion I had with a friend you get squared away*
219 *quickly. You say to yourself 'yes, I get it', the doctor told me but I didn't really do anything, but here*
220 *when someone gives you some real information it makes you react."* Participant 5, tetraplegic.

221 Individuals sought information from the supplier and people they knew who worked in the medical
222 field. The physician giving the SA diagnosis was rarely identified as a reliable source of
223 information.

224

225 *"Perceived level of severity"*

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

229 Conversely, most participants considered SA as a severe pathology, characterized by airflow
230 cessation that could be fatal, a chronic pathology that cannot be cured and a source of

231 cardiovascular risk. *“I should wake up, like a safety mechanism, I don’t know, to tell myself ‘hey*
232 *you’re dying now.’ ” Participant 3, tetraplegic*

233

234 Category 4: Level of adherence

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

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

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

252

253 **Discussion**

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

256 In the general population, the development of management of SA quickly identified the

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

281 The results of our study highlight the specificity of the SCI population in light of the
282 constraints perceived by participants, which are related to not just physical dependence, as

283 suggested by the few studies completed [21]. The issue of dependence related to installing the
284 device can concern individuals with tetraplegia without family or professional caregivers, but it
285 seems quickly resolved and largely secondary in light of the other constraints. The issue is mostly
286 based at a relationship level, especially with the life partner. The role of the bed partner in CPAP
287 adherence has been recognized in the general population [41,42]. The partner of the individual with
288 SCI is already involved in many activities of daily living, nursing care [43] and prevention of
289 secondary complications [44]. The apparition of these added constraints within the couple changes
290 the nature of the relationship and can increase the risk of separation or partner's exhaustion [45–47].

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

297 Several recommendations can be made for physicians in light of our study results. The
298 patient must be informed of the SA pathology at the time of SA diagnosis and during the care
299 management. This information is designed to help the patient understand SA and the symptoms
300 experienced and even be aware of the negative impact of SA on their quality of life. Knowledge of
301 the consequences of SA on one's health can also help the patient evaluate the severity of the
302 pathology to determine the appropriate actions to be implemented. The prescribing physician must
303 be more involved at the beginning of the treatment, when the device is being fitted. The first weeks
304 seem determinant in the adherence process. This support from prescribing physicians has several
305 objectives, to help the individual identify early on the benefits of the device and to reveal the
306 inconvenient material, technical or psychological constraints related to the device in order to solve
307 them quickly. If the patient lives with a partner, the partner should be involved early on in
308 consultations and the device fitting process. Partners have their own representations of apnea and

309 the device. They can be barriers to treatment adherence but also facilitators on whom the physician
310 can rely on. Finally, in our study, the information based on experience (i.e., from other patients with
311 SA undergoing CPAP therapy) was considered more reliable than the medical and technical
312 information. This information can influence the representations of the patient related to SA and the
313 device. The influence of a support group in which patients (beginners and experienced) could
314 exchange on adherence could be investigated. Future research could focus on a quantitative
315 approach, by evaluating the weight of these different categories in the adherence process and by
316 proposing an adherence scale to screen people with SCI at risk of giving up the device.

317

318 **Limitations**

319 Our study has several limitations. First, we chose not to include individuals with a Bilevel Positive
320 Airway Pressure (BiPAP) device because it can be an inclusion bias, selecting more severe clinical
321 situations: BiPAP is generally indicated for severe respiratory insufficiency with hypercapnia and in
322 second intention in SA. Second, recruitment involved only one centre, which could constitute a
323 recruitment bias, not representative of the CPAP therapies in this population. However, only 6 of the
324 17 participants were fitted for the CPAP device in our centre. A second implied recruitment bias
325 concerns the adherence profile of the participants. Even though the proportion of compliant
326 individuals matched the literature, we were not able to include individuals who gave up the CPAP
327 device. This bias in the representation of the sample is lessened by the fact that 2 participants,
328 qualified as non-compliant, definitely gave up the device in the months following the study. Finally,
329 an evaluation of sleep quality and depression would have been interesting to refine the
330 interpretation of the results. The last limitation is the lack of analysis regarding the mechanism of
331 SA (i.e., central or obstructive). To date, we are not able to exclude a potential effect of the SA
332 mechanism on CPAP adherence, and further studies should take this into account.

333 In summary, this study highlighted that, in addition factors of adherence to a CPAP device
334 similar to those identified in the general population, certain determinants are specific to individuals

335 with SCI: dependence on a third party for putting on the device and relationship implications,
336 increased care burden and additional medical equipment at home, which are already issues in this
337 population. These additional factors can explain the low rate of CPAP adherence in this population.
338 Personalized support and follow-up, taking into account these elements, should improve adherence
339 in this population.

340

341 **Conflict of interest.** None declared.

342

343 **Financial disclosure.** We certify that no party having a direct interest in the results of the research
344 supporting this article has or will confer a benefit to us or to any organization with which we are
345 associated AND, if applicable, we certify that all financial and material support for this research
346 (e.g., US NIH or NHS grants) and work are clearly identified in the title page of the manuscript.

347

348 **Legends**

349 **Figure 1.** Social cognitive model of Bandura.

350

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

353

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Figure 1:

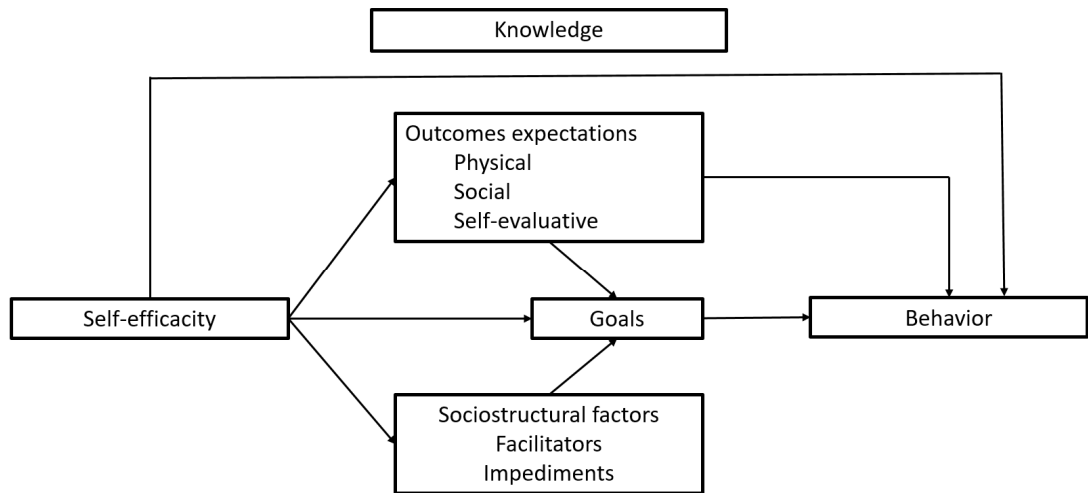


Figure 2:

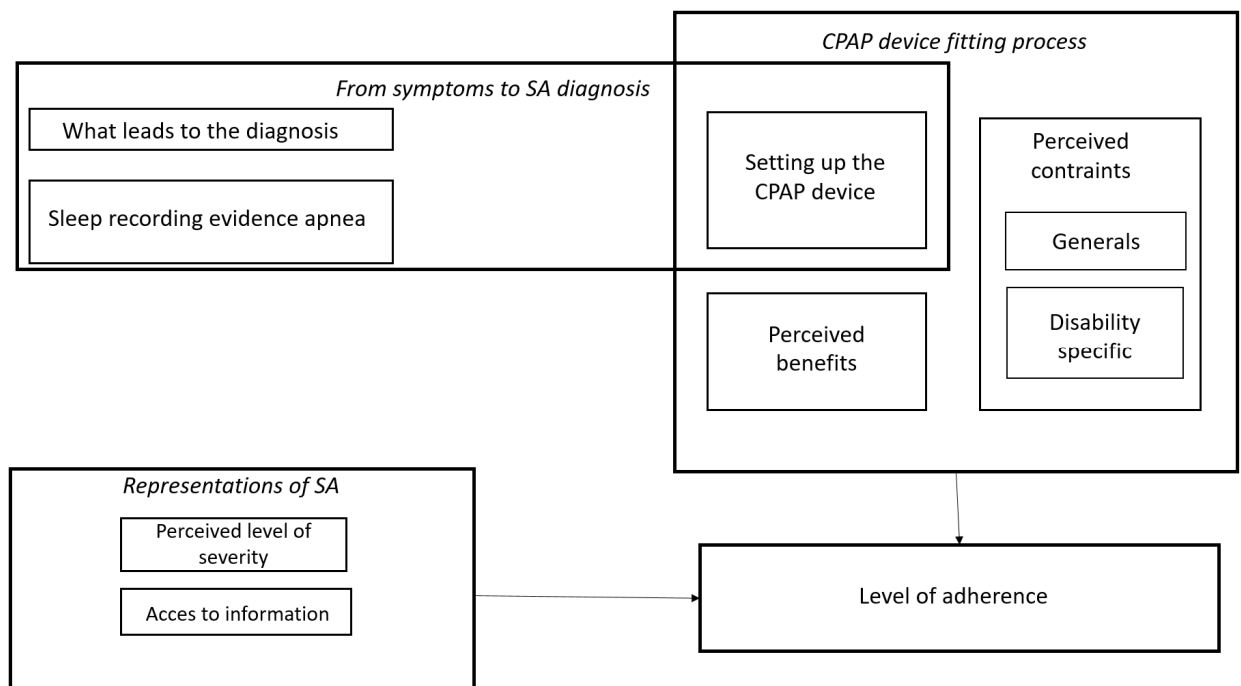


Table. Characteristics of participants with spinal cord injury and sleep apnea with continuous positive airway pressure treatment (n=17).

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