ORIGINAL ARTICLE

Impaired respiratory function and associations with health-related quality of life in people with spinal cord injury

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Study design: Follow-up measurement in a multicenter prospective cohort study.

Objectives: To examine the prevalence of impaired respiratory function (pulmonary function and perceived respiratory function), the incidence of respiratory infection and the associations among these parameters in people with spinal cord injury (SCI) 5 years after initial inpatient rehabilitation. Second, we assessed associations between respiratory function and health-related quality of life (HRQOL).

Setting: Eight rehabilitation centers with specialized SCI units in the Netherlands.

Methods: Measurements were performed 5 years after discharge of inpatient rehabilitation. Pulmonary function was determined by forced vital capacity (FVC) and perceived respiratory function by self-reported cough strength and dyspnea. HRQOL was measured using the Sickness Impact Profile 68 and the 36-item Short Form Health Survey.

Results: One-hundred forty-seven people with SCI participated. Of this sample, 30.9% had impaired FVC, 35.9% poor or moderate cough strength, 18.4% dyspnea at rest and 29.0% dyspnea during activity. In the year before the measurements, 8.9% had had respiratory infection. FVC was associated with cough strength, but not with dyspnea. All respiratory function parameters were associated with social functioning, whereas other HRQOL domains were associated with dyspnea only.

Conclusion: Five years after initial inpatient rehabilitation, impaired respiratory function and respiratory infection were common in people with SCI. More severely impaired respiratory function was associated with lower HRQOL.

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INTRODUCTION

Injury of the spinal cord affects the respiratory muscles, resulting in impaired respiratory function including low pulmonary function, weak cough strength and difficulty in breathing. The higher and more complete the injury, the more respiratory muscles are affected and the more respiratory function may be impaired.[1] In the early phase after injury, respiratory care is an essential part of medical and rehabilitation management, but respiratory care in the chronic phase may not be optimal. After all, respiratory complications such as respiratory infections continue to be an important cause of hospitalization and early death in people with chronic spinal cord injury (SCI) after the first year post onset.[2–4]

Previous studies showed impaired pulmonary function and cough strength in people with chronic SCI.[1,5] In addition, several studies have demonstrated that a sensation of breathlessness (dyspnea) is common (between 6 and 68% depending on the group studied) in people with chronic SCI.[6–9] However, most of these studies focused on one aspect of respiratory function or respiratory infection only and included people with a variable and long mean time after injury (longer than 10 years). Therefore, little is known about the effects of SCI in the early years after initial rehabilitation and about relationships between different aspects of respiratory function and their relationships with respiratory infection.

Respiratory function is not only relevant in itself and in association with respiratory infection, but also impaired respiratory function may affect one's health-related quality of life (HRQOL, including physical, mental and social aspects).[10] However, so far knowledge on this topic is scarce and results are inconsistent. Jain *et al.*[9] found significant associations between several respiratory symptoms and functioning (physical and social limitations), mood state and global quality of life; Jensen *et al.*[7] found significant associations between dyspnea and fatigue, but not between dyspnea and social integration or mental functioning. In addition, an association between pulmonary function and functioning, but not between pulmonary function and mood state or global quality of life, was found.[9]

Following the above, the aim of the present study was to examine the prevalence of impaired respiratory function (both objective pulmonary function and perceived respiratory function), the incidence of respiratory infection and the associations among these parameters in people with SCI 5 years after initial inpatient rehabilitation. The second aim was to assess the associations between respiratory function and HRQOL (expressed as: social functioning, general health, mental health and vitality).

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MATERIALS AND METHODS

Participants

For the present study, we used data of the 5-year follow-up measurement of the Dutch multicenter prospective cohort study 'restoration of mobility in spinal cord injury'.[11] The original cohort counted 225 participants at the first test occasion (start of initial inpatient rehabilitation) and inclusion criteria were a recent SCI, admission to one of the eight participating rehabilitation centers with specialized SCI units in the Netherlands from August 2000 to July 2003, between 18 and 65 years of age, grade A, B, C or D on the American Spinal Injury Association Impairment Scale (AIS)[12] and expected (partial) wheelchair dependency. Exclusion criteria were a progressive disease, a psychiatric condition or insufficient comprehension of the Dutch language. The follow-up 5 years after inpatient rehabilitation was approved by the medical ethics committee of the University Medical Centre Utrecht. All participants gave written informed consent.

Procedure

People included in the original cohort study were contacted and invited for this follow-up study 5 years after discharge from inpatient rehabilitation. Measurements used in the current study included an examination by a rehabilitation physician, a pulmonary function test by a trained research assistant, an oral interview and a mailed questionnaire.

Respiratory function

Respiratory function was operationalized by both pulmonary function (an objective measure) and perceived respiratory function (a subjective measure). Pulmonary function was determined by vital capacity, a measure often used as a general indicator of overall pulmonary function.[13] Vital capacity was measured with a computerized spirometer, the Oxycon Delta (CareFusion, Hochberg, Germany), during a forced vital capacity (FVC) maneuver. People were tested seated in their wheelchair and wearing a nose clip. Measurements were repeated three times; in case of a non-characteristic curve, an extra measurement was performed.[14] The trial with the highest sum of FVC and forced expiratory volume in 1 s was used for further analyses. FVC was expressed as a percentage of the predicted value based on able-bodied people of the same age, gender and height.[15]

Perceived respiratory function was expressed by self-reported cough strength and dyspnea. By means of a mailed questionnaire, people were asked 'How strong/weak is your cough strength in the seated position?'(answers: poor, moderate, fairly strong or strong) and 'How often did you experience breathlessness at rest in the previous month?'(answers: never, occasionally, regularly or often). The same question was asked for dyspnea during physical activity. This questionnaire was based on items included in the usual physicians and physical therapist's medical history. Its feasibility was tested on several patients before the start of this study.

Respiratory infections

A rehabilitation physician assessed, during a medical examination, the occurrence of secondary complications over the last 12 months.[16] Different symptoms of secondary complications were talked through with the patient. Physicians were instructed that only clinically important infections, in general lower tract respiratory infections (bronchitis and pneumonia), were to be registered as respiratory infection. The mild upper respiratory tract infections such as the common nose or head cold without fever were excluded.

Health-related quality of life

Four domains of HRQOL were measured. Social functioning was measured with the social dimension of the Sickness Impact Profile 68 (SIPSOC), which is the sum score of the subscales Mobility Range and Social Behavior.[17] The score range is 0–22; high scores reflect more limitations in social functioning. Furthermore, perceived General Health, Mental Health (psychological functioning) and Vitality (energy and fatigue) were measured with the corresponding subscales of the 36-item Short Form Health Survey questionnaire (SF-36).[18] The score range in each subscale was 0 (lowest) to 100 (highest). High scores reflect good general health, mental health and vitality. The Sickness Impact Profile 68 and SF-36 proved to be reliable and valid in people with SCI.[17,19,20]

Other variables

Lesion characteristics were determined according to the International Standards for Neurological Classification of Spinal Cord Injury.[12] People were classified by the lesion level—tetraplegia or paraplegia—and completeness of lesion: motor complete (AIS A or B) or incomplete (AIS C or D). In addition, the presence of concomitant respiratory conditions was scored if the physician had reported that the person suffered from a respiratory disease other than respiratory infection in the year before the measurement (that is, asthma, chronic obstructive pulmonary disease or pulmonary embolism) or if data from previous measurements showed that the person had a condition before or at the onset of SCI that was likely to affect pulmonary function largely (lobectomy, echinococcus in the lung tissue and Morbus Bechterew (Bechterew)).

Statistical analyses

A non-response analysis was performed by comparing baseline characteristics of participants of the present study with participants of the original cohort who did not complete the measurements 5 years after inpatient rehabilitation, by using independent Student's t-tests for continuous variables and Phi-Cramers' V tests for nominal variables.

Descriptive statistics were used to calculate the prevalence of impaired respiratory function and the incidence of respiratory infection. For further statistics, the dyspnea categories 'regularly' and 'often' were merged for reasons of group size and statistics. We compared the distribution of FVC across different categories of cough strength and dyspnea. In addition, we compared the distribution of FVC between those with and those without respiratory infection. For these associations, we used Kruskal–Wallis tests.

Linear regression analysis was used to study associations between respiratory function and HRQOL. Dependent variables were the different domains of HRQOL. Independent variables were the parameters of respiratory function: FVC, cough strength, dyspnea at rest and dyspnea during activity. For cough strength, the categories fairly strong, moderate and poor cough strength were entered as dummy variables (strong was used as a reference). For dyspnea, the categories regularly or often and occasionally were entered as dummies (never was used as a reference). To correct for SCI characteristics, lesion level (tetraplegia or paraplegia) and lesion completeness (motor complete or incomplete) were included as independent variables in this analysis first. For all analyses, the significance level was set at 0.05.

RESULTS

One-hundred forty-seven people with SCI participated in the Dutch multicenter prospective cohort study 5 years after inpatient rehabilitation. Their characteristics are presented in Table 1. All people breathed without (partial) mechanical support and were without tracheotomy. Nine people had concomitant conditions: chronic obstructive pulmonary disease ($n = 4$), asthma ($n = 1$), status after lobectomy due to lung cancer ($n = 2$), echinococcus in the lung

Table 1 Demographic characteristics ($N = 147$)

Age in years, mean (s.d.)	45.5 (13.8)
Gender, % men	71.4
Lesion group, n (%)	
Motor complete (AIS A and B) tetraplegia	33 (22.4)
Incomplete (AIS C and D) tetraplegia	21 (14.3)
Motor complete (AIS A and B) paraplegia	67 (45.6)
Incomplete (AIS C and D) paraplegia	26 (17.7)
Cause of injury, % traumatic	78.9
Time since injury in years, mean (s.d.)	6.6 (0.8)
Smoking status, % current smokers	23.2

Abbreviation: AIS, American Spinal Injury Association Impairment Scale.

tissue ($n = 1$) and Bechterew ($n = 1$). One person had had a pulmonary embolism within the year before the measurement. Seventy-eight participants of the original cohort were lost to follow-up for several reasons: 27 died, 18 refused to collaborate, 5 moved abroad, 11 could not be contacted and the rest had other or unknown reasons for dropping out of the study.[16] Participants of the present study did not significantly differ from participants of the original cohort who did not complete the measurements 5 years after inpatient rehabilitation (the non-participants, $n = 78$) concerning gender, lesion level and completeness of lesion. However, the participants were on average younger than the non-participants (mean age 39.2 years vs 43.4 years old; $P = 0.04$), and in this group the cause of SCI was more often traumatic (78.9 vs 63.6%; $P = 0.01$).

Table 2 shows that 30.9% of all people had impaired FVC (below 80% of the predicted value), 35.9% perceived poor or moderate cough strength and 18.4% (at rest) and 29.0% (during activity) experienced dyspnea (occasionally, regularly or often). During the year before the measurements 12 people had had respiratory infection, of whom 7 had been confined to bed for at least 1 day and 5 had been hospitalized (unknown, 7, 7, 8 and 21 days).

The distribution of percent predicted that FVC differed between cough strength categories: strong: median (interquartile range) 101.4% (89.6–112.4), fairly strong: 86.3% (77.1–103.9), moderate: 86.3% (76.9–94.3) and poor: 72.9% (52.1–83.4), $P = 0.000$ (Figure 1). No significant difference was found between dyspnea categories and between people with and without respiratory infection.

Associations between parameters of respiratory function and domains of HRQOL are presented in Table 3. When corrected for the lesion level and completeness, people with lower FVC, poor perceived cough strength and more dyspnea reported more limitations in social functioning. In addition, in our sample, people with dyspnea reported lower general health, mental health and vitality. Parameters of respiratory function contributed to 2–6% of the explained variance in the associations found.

DISCUSSION

The present study showed that impaired respiratory function and respiratory infection were common in people 5 years after inpatient rehabilitation for SCI. In addition, several associations between (impaired) respiratory function and domains of HRQOL were found.

Incidence of impaired respiratory function and respiratory infection

The prevalence of impaired respiratory function was considerable in our study. However, severe impairments were less common: only 8.8% of people had severely impaired FVC ($<60\%$ predicted value), 15.8% gave their cough strength the lowest possible rating (poor) and few people (3% in sit and 5% during activity) experienced dyspnea regularly or often. The prevalence rates of dyspnea found in our study are higher than reported in a large European general population study (5.7% dyspnea in rest and 17.5% after exercise),[10] but lower than in previous SCI studies.[6–8] Detailed comparison with other SCI studies

Table 2 Prevalence of impaired respiratory function and incidence of respiratory infections for the whole study group and the per lesion group

	All (n = 147)	CT (n = 33)	IT (n = 21)	CP (n = 67)	IP (n = 26)
Percent predicted FVC, mean (s.d.)	89.8 (20.5)	76.9 (16.7)	96.7 (23.6)	91.1 (18.5)	96.9 (22.0)
FVC (n = 113)					
Not impaired (⩾ 80.0% predicted FVC)	78 (69.0)	12[(1)a]	9[(1)]	41[(2)]	16
Mildly impaired (60–80% predicted FVC)	25 (22.1)	8[(1)]	3	11[(2)]	3
Severely impaired (<60% predicted FVC)	10 (8.8)	4	1	3	2[(2)]
Cough strength (n = 139)					
Strong	45 (32.4)	1	3[(1)]	21[(2)]	20
Fairly strong	44 (31.7)	11	5	24[(2)]	4
Moderate	28 (20.1)	10[(1)]	4	14	0
Poor	22 (15.8)	10[(1)]	6	5[(1)]	1[(1)]
Dyspnea at rest (n = 136)					
Never	111 (81.6)	22[(1)]	15[(1)]	51[(3)]	23[(1)]
Occasionally	21 (15.4)	9	2	9[(2)]	1
Regularly	2 (1.5)	0	0	1	1
Often	2 (1.5)	1[(1)]	0	1	0
Dyspnea during physical activity (n = 138)					
Never	98 (71.0)	24[(1)]	12[(1)]	43[(3)]	19[(1)]
Occasionally	33 (23.9)	7[(1)]	5	17[(1)]	4
Regularly	5 (3.6)	1	1	1	2
Often	2 (1.4)	0	0	2[(1)]	0
Respiratory infection in the year prior (n = 135)					
No	123 (91.1)	28[(2)]	15[(1)]	57[(5)]	23
Yes	12 (8.9)	4	2	5	1[(1)]

Abbreviations: CP, motor complete paraplegia; CT, motor complete tetraplegia; FVC, forced vital capacity; IP, incomplete paraplegia; IT, incomplete tetraplegia.
Note: For percent predicted FVC means (s.d.) are presented. All other values are the number of people (%).
[a]The number of people with concomitant respiratory illnesses (asthma, chronic obstructive pulmonary disease and a status after lobectomy) in each lesion group is presented within brackets.
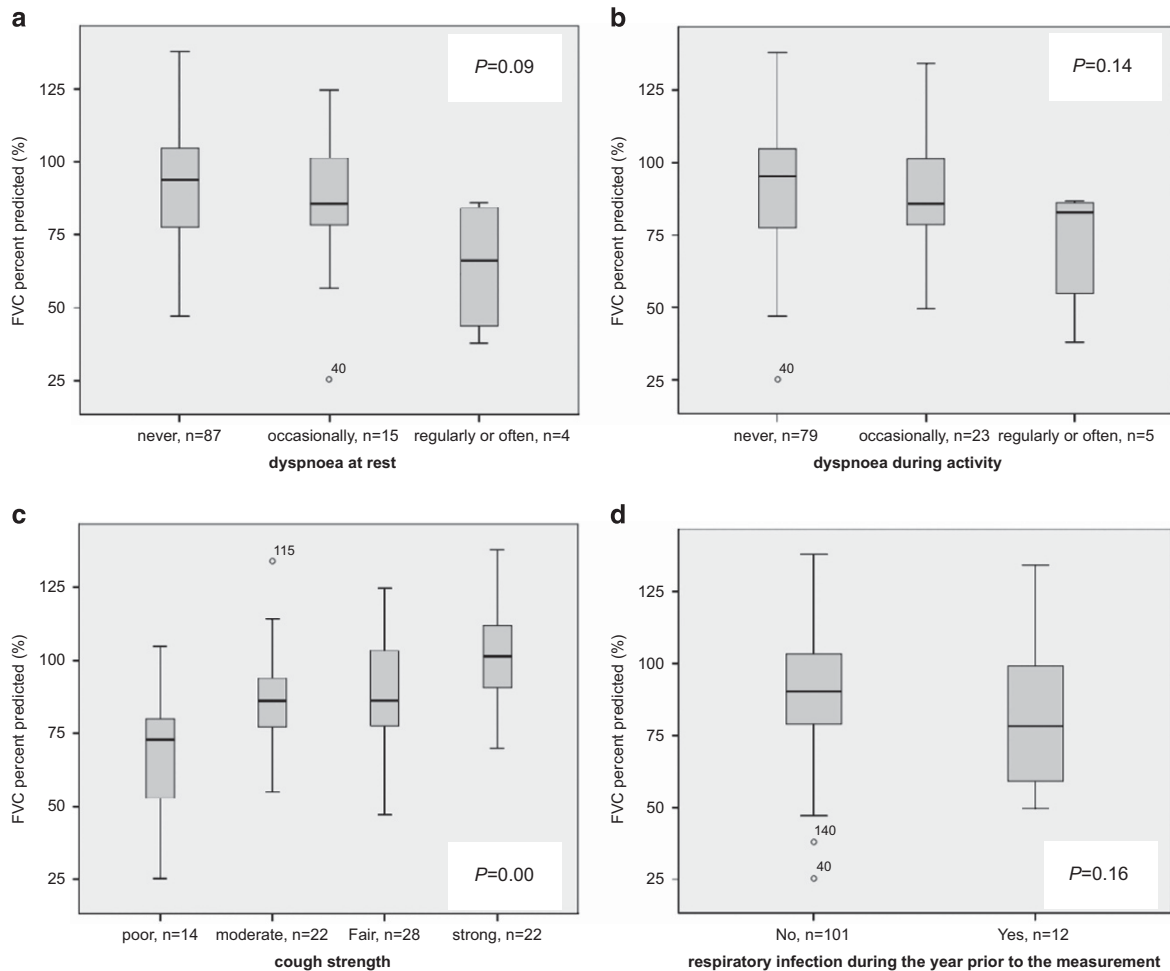
Figure 1 Distribution of FVC across different categories for dyspnea at rest (a), dyspnea during activity (b), cough strength (c) and between groups with and without respiratory infection (d). Note: Boxplots present median score (-), interquartile range (gray) and minimum and maximum range (whiskers).

was not possible because of differences in the definitions of dyspnea, outcome measures and group compositions. Therefore, it is impossible to conclude whether prevalence rates in the early years after rehabilitation (our study population) are different from prevalence rates in long-standing SCI (over 10 year post onset). However, similar to previous findings, our results showed that dyspnea at rest was reported more in people with complete tetraplegia compared with other lesion groups, whereas dyspnea reported during activities was spread evenly over all lesion groups.[6,8] The most likely explanation for this finding seems that the excess of functional loss prevents people with tetraplegia to be active in such a manner that the respiratory system is challenged.[21] This explanation is supported by additional data collected in this cohort. Measured with the 'Physical Activity Scale for Individuals with Physical Disabilities',[22] people with complete tetraplegia were less physical active (median score (interquartile range) 10 (1–14) metabolic equivalent value per hours per day (MET h per day) compared with people in other lesion groups (incomplete tetraplegia: 22 (5–39); complete paraplegia: 16 (7–32); and incomplete paraplegia: 19 (9–34) MET h per day). In addition, we found that in people with extremely low activity levels (below 10 MET h per day) dyspnea during activity were reported as often as in rest (13 people), whereas in people who are more active the prevalence of dyspnea during activity was twice as high (24 people) as in rest (11 people). In contrast to what is often believed, this study showed that impaired

respiratory function and respiratory infection were not solely a problem of people with complete tetraplegia. We found that impaired pulmonary function, weaker cough strength, dyspnea and respiratory infections were more common in people with complete tetraplegia. However, these problems also occurred in many people with less severe neurological deficits even after correcting for those with concomitant respiratory illnesses (asthma, chronic obstructive pulmonary disease and a status after lobectomy). Therefore, respiratory care after inpatient rehabilitation should not only focus on people with complete tetraplegia, but also on all people who have impaired respiratory function.

The incidence of respiratory infection in the fifth year after inpatient rehabilitation (8.9%) was similar to that in the first year after rehabilitation in the same cohort[23] and to that reported in other chronic SCI populations.[3,24,25] The incidence found in the present study is considerably higher than in the general Dutch population (estimated incidence rate for lower tract respiratory infection was 2.9).[26] Moreover, the incidence of hospitalization due to respiratory infection (3.7%) was approximately 10 times higher. This, in addition to the knowledge that eight people of the original cohort ($n = 225$) died because of respiratory complications before this measurement,[27] shows that people with chronic SCI are not only more susceptible to respiratory complications, but also that these complications also seem to have larger consequences.

Table 3 Associations between respiratory function and domains of health-related quality of life (HRQOL) corrected for the lesion level and completeness

Mean ± s.d. for all	SIPSOC range: 0–22 6.7 ± 4.7		General health range: 0–100 60.7 ± 23.3		Mental health range: 0–100 77.5 ± 15.1		Vitality range: 0–100 65.7 ± 16.2	
Variables	β ± s.e.	P	β ± s.e.	P	β ± s.e.	P	β ± s.e.	P
FVC[a]								
10% predicted	−0.5 ± 0.2	0.04	1.2 ± 1.1	0.29	0.5 ± 0.8	0.52	0.6 ± 0.8	0.46
Cough strength[b]								
Fairly strong	−0.2 ± 1.0	0.86	−7.5 ± 5.4	0.16	−2.6 ± 3.5	0.46	−0.4 ± 3.8	0.91
Moderate	0.6 ± 1.2	0.61	−9.4 ± 6.3	0.13	−2.7 ± 4.1	0.51	−2.2 ± 4.4	0.62
Poor	3.3 ± 1.3	0.02	−7.7 ± 7.0	0.27	−6.9 ± 4.6	0.14	−2.8 ± 5.0	0.59
Dyspnea at rest[b]								
Occasionally	1.6 ± 1.1	0.13	−12.1 ± 5.5	0.03	−1.1 ± 3.8	0.77	−5.9 ± 4.1	0.15
Regularly or often	6.8 ± 2.2	0.00	−27.6 ± 11.5	0.02	−16.0 ± 7.7	0.04	−14.4 ± 8.2	0.08
Dyspnea during physical activity[b]								
Occasionally	1.3 ± 0.9	0.14	−10.8 ± 4.6	0.02	−8.4 ± 3.0	0.01	−9.1 ± 3.3	0.01
Regularly or often	5.4 ± 1.7	0.00	−18.8 ± 8.9	0.04	−12.7 ± 5.8	0.03	−12.0 ± 6.1	0.05

Abbreviations: FVC, forced vital capacity; s.e., standard error; SIPSOC, social dimension of the Sickness Impact Profile 68.
[a]The regression coefficients (β) represent the change in outcome (HRQOL score) associated with an increase in 10% predicted FVC.
[b]The regression coefficients (β) represent the difference in outcome (HRQOL score) between, respectively, fairly strong, moderate or poor cough strength and strong cough strength and between, respectively, occasionally or regularly present dyspnea and no dyspnea.

Associations among parameters of respiratory function

This study showed that there was no association between FVC and reported dyspnea. The lack of a relationship between objectively measured respiratory function and perceived respiratory function may be one of the reasons that people with SCI rarely refer to their respiratory impairments as a problem.[28] Possibly people with SCI may become accustomed to their limitations or, as previously suggested, motor impairments due to peripheral paresis may prevent them to challenge their cardiorespiratory system.[21] As a result, people may not be sufficiently aware of their impaired respiratory function and may not seek medical care when necessary. This is in particularly worrisome in the light of earlier findings in the same cohort: we found that a large proportion (28.3%) of the present study group suffered from a larger than normal age-related decline in FVC between the first and fifth year after discharge of inpatient rehabilitation.[29] Regular follow-up care addressing respiratory function may prevent people from entering a downward spiral with increasing risk of severe respiratory complications.

Associations between respiratory function and HRQOL

In the present study, several associations between parameters of respiratory function and HRQOL domains were found. All studied respiratory function parameters were associated with social functioning, and dyspnea (at rest and/or during activity) was associated with all studied HRQOL domains. Mean scores for HRQOL in people with severely impaired respiratory function were notably worse. People who experienced dyspnea regularly or often scored on average 12–30% (of the theoretical score range) lower on HRQOL domains compared with people without dyspnea. In addition, a decline of FVC that surpasses the normal age-related decline may lead to negative changes in social functioning over the years (2% for each decline of 10% predicted FVC). The associations found in our study were largely in agreement with conclusions in previous studies.

For example, Jain et al.[9] found that FVC was associated with functioning (physical and social limitations), whereas self-reported respiratory symptoms were associated with multiple HRQOL domains. In contrast, the association between dyspnea and mental health was not found in other studies.[7,9] The results found in our and in previous studies suggest that respiratory function is of importance for HRQOL.

When interpreting these results, we have to realize that the parameters of respiratory function explained only 2–6% of the variance in HRQOL. However, HRQOL is a difficult and a complex concept that depends on many sociodemographic, psychosocial, health and disability-related variables. There is not one variable that explains the variance of HRQOL at large.[30–32] Nevertheless, HRQOL is an important outcome in rehabilitation; and therefore, the associations found in our study may be clinically relevant.[33] Every small change in reported quality of life may mean a lot for the individual patient.

Limitations

A limitation of the present study was that FVC was not determined in all people. This may have lowered statistical power. In addition, it is possible that especially the more vulnerable people were not able or willing to come to the rehabilitation center for measurements and therefore did not perform pulmonary function tests. This may have led to underestimation of impaired respiratory function. Contrary, only people who were wheelchair dependent were included in this study, which may have led to overestimation. In addition, in order to have a realistic representation of the SCI population, the 10 people with concomitant respiratory conditions were not excluded. This may have affected the prevalence and incidence rates. However, post hoc analysis with exclusion of these people did not change the associations found. Furthermore, the questionnaire concerning perceived respiratory function (dyspnea and cough strength) was subjective and not tested for reliability, validity or ceiling effects. However, in

clinical practice, subjective information on respiratory function is often used as an indicator for the need of more objective measurements of respiratory function. Therefore, in our opinion, it was relevant to study perceived respiratory function in addition to objectively measured respiratory function. The results showed that simply asking the patient whether they experience dyspnea is not enough. These subjective questions need to be combined with objective measurements. Finally, because of the cross-sectional nature of the present study, conclusions on the direction of the relationships found cannot be made.

Clinical implications

Respiratory function impairments were present in all lesion groups. This indicates the need to monitor respiratory impairments in all people with SCI irrespective of lesion characteristics. Furthermore, relationships found in our sample may suggest that maintaining good respiratory function may not only help prevent respiratory infection but may also add to HRQOL.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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