

Care of the patient with end-stage chronic respiratory failure: the perspective of the caregiver

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Received: 28 April 2008 / Accepted: 30 June 2008 / Published online: 25 May 2009
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Abstract The possibility of prolonging and augmenting the quality of life of respiratory patients in end-stage disease depends on an increased level of care. This situation has increased the number of patients dependent on long-term therapies assisting pulmonary function such as

chronic oxygen supply or mechanical ventilation. A specifically designed questionnaire was administered to caregivers to analyse the level of care provided to these patients in seven respiratory disease centres of Northern Italy. The study population consisted of 72 patients (45 males and 27 females) with at least 8 years of oxygen therapy and 1 year of mechanical ventilation (patients with sleep apnoea treated with continuous positive airway pressure-CPAP- were excluded). Of the 72 patients, 17 were being treated with oxygen therapy, 4 with mechanical ventilation and 51 with mechanical ventilation plus oxygen. The questionnaire was divided in two parts: questions 1 to 13 investigated life conditions and 14 to 22 the quality of care provided. The patients studied present a heavy burden of care and this is in relation to the quantity of respiratory aids prescribed. The symptom which created statistically significant problems for care was dyspnoea, as is often reported in the literature. The presence of home care tended to create conditions of greater serenity for the caregivers. This study shows that the burden of care in severe respiratory patients is very onerous, and it can help to point out problems not sufficiently contemplated in healthcare planning in Italy.

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Keywords Chronic respiratory failure · Mechanical ventilation · Caregiver

Introduction

The improvement of medical care techniques is increasing the number of end-stage respiratory patients dependent on the continuous administration of oxygen therapy and possibly also mechanical ventilation. This situation is contrasted with a modified social and family organisa-

tion which is not always ready and prepared to sustain this burden of care [1, 2]. Symptoms of depression, lifestyle changes and a reduction in working hours are constant findings among caregivers of family members with severe respiratory problems [2, 3]. The literature also reports of the significant economic burden and provision of care which the family must sustain in a chronic setting such as the end-stage respiratory patient [1, 3, 4]. In addition, the increasing need for care and surveillance of these patients is also well known [2, 3, 5]. This has prompted numerous studies which have evaluated either the psychosocial condition of the caregivers [3, 4] or the quality of care seen from the perspective of the patient [6]. The novelty of our study is the evaluation of:

- the perception of the caregiver in terms of the state of health of their loved one;
- their perception of the degree and quality of care provided;
- the socioeconomic situation of the caregiver of patients affected by severe respiratory disease subject to home oxygen therapy and/or mechanical ventilation.

Materials and methods

We enrolled 72 patients (45 males and 27 females) affected by end-stage respiratory failure included in a treatment programme of long-term oxygen therapy (at least 8 years) or prolonged mechanical ventilation (at least one year, associated with or without oxygen therapy). Of the 72 patients 17 were on oxygen therapy alone, 4 on mechanical ventilation alone and 51 on mechanical ventilation with associated oxygen therapy. The diseases included chronic obstructive pulmonary disease (COPD) (62 patients), restrictive lung disease (4 patients), amyotrophic lateral sclerosis (4 patients) and neuromuscular diseases (2 patients). Patients with respiratory disturbances during sleep who were using CPAP were excluded from the study.

A specially designed questionnaire was administered to each caregiver. The questionnaire was proposed directly to the caregiver during a routine check-up of the patient. The aims of the study were clearly illustrated by a healthcare worker who was not involved in the care of the patient and the material was returned anonymously to a non-healthcare worker at each centre. The results of the questionnaire were processed independently by an operator external to the study. The questionnaire has been reproduced in Table 1 and can be divided into two main parts. Questions 1 to 13 investigate the life conditions of the patient and caregiver, while questions 14 to 22 seek the views of the caregiver in terms of the care received from the national healthcare system and from the physician who discharged the patient.

The first part of the questionnaire is further divided into two subgroups. The first analyses the lifestyle changes the caregiver had made (e.g. possible changes in the type of work, economic problems and the possible support received from other persons such as family or friends). The second subgroup of questions investigates the impact and psychological burden derived from caring for a person with a progressive and invalidating disease. The second part of the questionnaire, which as stated sought the perception of the quality of care received, was aimed at quantifying the relative level of satisfaction with the care provided by the centre where the patient was treated, from the home nursing service and lastly from the patient's general practitioner, with particular reference to possible problems regarding the use of respiratory support systems at home and the real availability of the various healthcare workers. The questionnaire was drawn up by a group of pulmonologists operating in 7 different respiratory centres in North Italy dedicated to the treatment of patients with chronic respiratory failure. The questions of the questionnaire were processed and agreed upon by the physicians involved in the study.

Statistical analysis

A descriptive analysis of the case series was performed with the Snedcor-Fisher F-test to evaluate the statistical differences between the group of patients with a greater number of prescribed respiratory aids (mechanical ventilation + oxygen therapy = group A) and the group of patients with only one of the two aids prescribed (lesser prescribed need = group B) as well as a non parametric stratified analysis with the Pearson chi-squared test. The two groups were compared to investigate the difference of factors associated with burn out of the caregiver (Table 2), difficulty of the caregiver (Table 3) or factors possibly involved in producing or upsetting the serenity of the caregiver (Table 4). Findings were considered significant for $p < 0.05$.

Results

Seventy-two caregivers responded to the questionnaire (100% of interviewees). The responses showed that in most cases patients are cared for by a close relative (usually the spouse). Caregivers had to frequently modify their work choices or lifestyle as well as suffer the burden of increased expenses due mainly to the cost of transporting the patient. The responses also revealed that the care provided to the patient, both by the various healthcare facilities and the patient's general practitioner, was considered satisfactory for nearly all of the respondents.

Tables 1–4 summarise the main findings. The two groups studied were statistically different in both the presence and duration of oxygen therapy as well as the presence of mechanical therapy. The two groups were not different in influencing the sense of burnout, of excessive burden of care, or in contrast in creating conditions of serenity for the caregiver (Table 1).

Table 2 shows that none of the factors associated with burn out of the caregiver reached statistical significance. Burnout was present in 36% of the respondents, although this does not seem to be influenced by the patient’s symptoms, the burden of care or the care provided by the healthcare services. In contrast some factors are significantly present, thus dividing the caregivers into those with or without difficulty in providing care (Table 3). When present, dyspnoea proved to be a management problem in the group of caregivers with difficulty, whereas the presence of homecare was more commonly associated with caregivers who perceived no difficulties in providing care.

Table 4 shows that the presence of a greater burden of care is significantly present in the caregivers with difficulties in relation to which external factors such as medical care or the support of other people, do not seem to help.

Discussion

This study shows that the burden of care for severe respiratory patients is extremely onerous, with a significant impact for the caregiver. These findings confirm other studies which have emphasised that the main problems encountered by caregivers are lifestyle changes, reduction in work activity and onset of symptoms of depression [3, 4], with a degree of severity comparable to that experienced by caregivers of patients with Alzheimer’s disease [4]. It is also known that the quality of life of patients with end-stage COPD (the majority of our patients) is worse than in patients suffering from chronic heart failure or

Table 1 Description of cases (N. 70)

	OT and MV		OT or MV		p value*	
	n	%	n	%		
Women	19	42.2	7	28.0	0.31	
Main respiratory disease					0.69	
	COPD	41	91.1	22	88.0	
	Restrictive	4	8.9	3	12.0	
Oxygen therapy present		45	100.0	20	80.0	< 0.01
Duration oxygen therapy	5 years or less	22	48.9	3	15.0	0.01
2	More than 5 years	23	51.1	17	85.0	
Mechanical ventilation present		45	100.0	5	20.0	< 0.01
Duration mechanical ventilation	3 years or less	25	55.6	2	40.0	0.65
	More than 5 years	20	44.4	3	60.0	
Hospitalized at least once in last 3 months		24	53.3	15	60.0	0.62
Caregiver reports “burn-out”		18	40.0	7	28.0	0.44
Caregiver reports “difficulty”		32	71.1	14	56.0	0.29
Caregiver reports sense of “serenity”		6	13.3	6	24.0	0.14

OT, oxygen therapy; MV, mechanical ventilation
 *Snedcor-Fisher F-test

Table 2 Factors associated with caregiver’s burn-out

	N.	Sense of “burnout”				p value*
		Yes		No		
		n	%	n	%	
Support from other persons present (Q. 2)	70	9	36.0	25	55.6	0.14
Availability of healthcare benefits	43	7	43.8	6	22.2	0.18
Excessive economic burden for the care	55	2	14.3	9	22.0	0.71
Support of friends, relatives, religious or other present	70	13	52.0	29	64.4	0.32
Dyspnoea frequent symptom (Q. 9a)	70	19	76.0	32	71.1	0.78
Anxiety or depression	70	10	40.0	18	40.0	1.00
Index of healthcare burden relevant	70	9	36.0	11	24.4	0.41
Respiratory disease centre assistance judged excellent (Q. 17a)	69	19	76.0	37	84.1	0.52
Integrated homecare service proposed and activated (Q. 18)	64	12	57.1	19	44.2	0.43
Local healthcare centre homecare programme satisfactory (Q. 19)	30	3	27.3	7	36.8	0.70
Support provided by nurses judged satisfactory (Q. 20)	30	5	50.0	13	65.0	0.46

Q. question

Table 3 Factors associated with caregiver's difficulty

	N.	Sense of difficulty				p value*
		Yes		No		
		n	%	n	%	
Support from other persons present (Q. 2)	70	22	47.8	24	52.2	1.00
Availability of healthcare benefits	43	8	33.3	5	26.3	0.74
Excessive economic burden for the care	55	9	27.3	2	9.1	0.17
Support of friends, relatives, religious or other present	70	28	60.9	14	58.3	1.00
Dyspnoea frequent symptom (Q. 9a)	70	39	84.8	12	50.0	0.00
Anxiety or depression	70	21	45.7	7	29.2	0.21
Index of healthcare burden relevant	70	14	30.4	6	25.0	0.78
Respiratory disease centre assistance judged excellent (Q. 17a)	69	39	84.8	17	73.9	0.33
Integrated homecare service proposed and activated (Q. 18)	64	15	36.6	16	69.6	0.02
Local healthcare centre homecare programme satisfactory (Q. 19)	30	3	20.0	7	46.7	0.25
Support provided by nurses judged satisfactory (Q. 20)	30	7	46.7	11	73.3	0.26

Q, question

Table 4 Factors associated with caregiver's serenity

	N.	Sense of serenity				p value*
		Yes		No		
		n	%	n	%	
Support from other persons present (Q. 2)	70	6	50.0	28	48.3	1.00
Availability of healthcare benefits	43	2	20.0	11	33.3	0.70
Excessive economic burden for the care	55	1	8.3	10	23.3	0.42
Support of friends, relatives, religious or other present	70	7	58.3	35	60.3	1.00
Dyspnoea frequent symptom (Q. 9a)	70	6	50.0	45	77.6	0.07
Anxiety or depression	70	3	25.0	25	43.1	0.34
Index of healthcare burden relevant	70	0	0.0	20	34.5	0.01
Respiratory disease centre assistance judged excellent (Q. 17a)	69	11	91.7	45	78.9	0.44
Integrated homecare service proposed and activated (Q. 18)	64	8	66.7	23	44.2	0.21
Local healthcare centre homecare programme satisfactory (Q. 19)	30	4	57.1	6	26.1	0.18
Support provided by nurses judged satisfactory (Q. 20)	30	7	87.5	11	50.0	0.10

lung cancer [7, 8]. In addition, it should be noted that patients with COPD usually receive less homecare and palliative treatment than patients with lung cancer [9].

Despite the full participation of the caregivers in filling out the questionnaire, this study has a number of limitations. The study was conducted in respiratory centres in North Italy and therefore cannot provide a complete picture of the Italian situation. Another limitation is the fact that the pulmonologists who participated in the study dedicate most of their activity to the care of chronic respiratory patients and this could in some way produce a more positive result than in other less dedicated respiratory settings. In previous studies non-Italian authors have attempted to describe the level of care of patients with advanced chronic respiratory failure [5, 7–11], but only in rare cases have attempts been made to evaluate the impact of the disease on their life conditions [2].

Conclusions

This study shows that the burden of care in severe respiratory patients is very onerous, with a significant impact for the caregiver. It may contribute to highlight a problem which is still not sufficiently recognised by the general public and healthcare planners in Italy by providing suggestions for the formulation of increasingly effective healthcare responses.

Riassunto Come e' noto la possibilita' di allungare e migliorare la qualita' della vita per i malati respiratori allo stadio avanzato di malattia e' legata a un incremento del livello di assistenza: tale situazione ha aumentato il numero dei pazienti legati alla somministrazione cronica di terapie che supportino la funzione polmonare quali l'ossigenoterapia o la ventilazione

meccanica. Attraverso un questionario formulato ad hoc abbiamo voluto analizzare, in 7 centri pneumologici del Nord Italia, la condizione di assistenza di questi malati tramite quanto riferito dai loro caregivers. Sono stati reclutati 72 pazienti (45 maschi – 27 femmine) in ossigenoterapia da almeno 8 anni o in ventilazione meccanica associata o meno ad ossigenoterapia (i pazienti con sindromi ostruttive del sonno che praticavano CPAP sono stati esclusi). La tipologia dei malati inseriti era la seguente: 17 pazienti in ossigenoterapia, 4 in sola ventilazione meccanica e 51 in ventilazione meccanica + arricchimento di ossigeno. Il questionario sottoposto era diviso in due raggruppamenti di domande: dalla domanda 1 alla 13 sono state approfondite le condizioni di vita del paziente (comprese quelle del caregiver) e dalla domanda 14 alla 22 la qualità percepita dell'assistenza ricevuta. I pazienti studiati presentano un grave carico assistenziale e ciò è in relazione con la quantità di presidi respiratori prescritti. Il sintomo che ha staticamente condizionato una maggiore difficoltà all'assistenza è stata la dispnea come spesso viene indicato in letteratura. La presenza di assistenza domiciliare (ADI) ha procurato una maggiore serenità nell'assistenza da parte dei caregivers. Questo studio mette in evidenza che il carico assistenziale per i malati respiratori severi risulta essere estremamente pesante con risvolti importanti per chi li assiste. Questo studio può contribuire ad evidenziare un problema non ancora sufficientemente considerato a livello di pianificazione sanitaria nella nostra Nazione.

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Appendix 1 : The Questionnaire

PART 1. PATIENT CONDITIONS

1. *Who is the main caregiver?*
 - a. Family member
 - b. Family members + integrated homecare
 - c. Paid caregiver
 - d. Other (voluntary
2. *Are you supported by other persons (friends, relatives) in caring for your family member?*
 - a. YES
 - b. NO
- 3a. *Have you had to change your work choices to care for your relative?*
 - a. YES
 - b. NO

Cont. →

Cont. Questionnaire

-
- 3b. *If you were able to have more time off from work, would you accept to provide additional care to your relative?*
- YES
 - NO
4. *Does the current situation involve additional expenses?*
- YES
 - NO
5. *If YES why?*
- Equipment (bed, wheelchair)
 - Material for ventilation or tracheostomy
 - Visits to specialists
 - Home nursing
 - Medication
 - Paid homecare
 - Transport
6. *Do you have serious economic problems in sustaining this situation?*
- YES
 - NO
7. *How would you describe your current frame of mind in caring for your relative?*
- Denial
 - Uncertainty
 - Insecurity
 - Anger
 - Resignation
 - Fatigue
 - Serenity
 - Difficulty
8. *Has the patient had support of some other kind during this period?*
- None
 - Religious
 - Friends
 - Voluntary association
 - Other.....
9. *What is the most frequent symptom the patient suffers?*
- Breathlessness
 - Chest pain
 - Increased secretions
 - Sleep disturbances
 - Headache
 - Mental confusion
 - Anxiety
 - Depression
 - Abdominal pain
 - Constipation
 - Other.....
10. *Are you aware of a progressive worsening of the patient's disease?*
- YES
 - NO
11. *Do you believe the patient is aware of the severity of the prognosis of his/her disease?*
- YES
 - NO
 - I DON'T KNOW
12. *If YES, who explained the severity and the prognosis of the disease to the patient?*
- The general practitioner
 - The specialist
 - Other
13. *Have you had difficulties using the prescribed respiratory support?*
- YES
 - NO
-

Cont. →

Cont. Questionnaire

PART 2. PERCEIVED QUALITY

14. *Has the patient been hospitalized in the last three months?*
 - a. YES (no. of times)
 - b. NO
 15. *What was the reason for the hospitalization?*
 - a. Respiratory problems
 - b. Heart problems
 - c. Nutritional problems
 - d. Other.....
 16. *Onto which ward was the patient admitted?*
 - a. Intensive care
 - b. Respiratory
 - c. General medicine
 - d. Emergency
 - e. Other.....
 17. *How would you evaluate the assistance provided by the respiratory disease centre?*
 - a. Unsatisfactory
 - b. Satisfactory
 - c. Good
 - d. Excellent
 18. *Has integrated homecare ever been proposed?*
 - a. YES
 - b. NO
 19. *If YES, how would you evaluate the programme of homecare provided by your local healthcare centre?*
 - a. It is a very satisfying service, even better than I expected
 - b. It is a quite satisfying service in line with my expectations
 - c. It is a relatively satisfying service
 - d. It is not a very satisfying service
 - e. It is a completely unsatisfying service, much worse than I expected
 20. *Are you satisfied with the support provided by the nurses?*
 - a. YES, I am completely satisfied
 - b. YES, I am partially satisfied
 - c. I am neither satisfied nor unsatisfied
 - d. NO, I am partially unsatisfied
 - e. NO, I am totally unsatisfied
 21. *Were you unable to contact your general practitioner or nurse at any time?*
 - a. YES very often
 - b. YES often
 - c. YES occasionally
 - d. Rarely
 - e. NO never
 22. *Are you satisfied with the support provided by your general practitioner in this period?*
 - a. YES, I am completely satisfied
 - b. YES, I am partially satisfied
 - c. I am neither satisfied nor unsatisfied
 - d. NO, I am partially unsatisfied
 - e. NO, I am totally unsatisfied
-