

Living with advanced chronic obstructive pulmonary disease: A qualitative interview study with patients and informal carers

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The authors have no conflict of interest to declare.

Abbreviations: COPD = chronic obstructive pulmonary disease, P = patient, IC = informal carer

Keywords: COPD, palliative care, stigma, care complexity

Abstract

The disease trajectory in chronic obstructive pulmonary disease (COPD) is characterised by a progressive decline in overall function, loss of independence and reduction of health-related quality of life. Although the symptom burden is high and care is often demanding, patients' and informal carers' experiences in living with advanced COPD are seldom described. This study sought to explore patients' and informal carers' experiences in living with advanced COPD and to understand their awareness about palliative care provision in advanced COPD. 20 patients and 20 informal carers were recruited in a respiratory care service in Southern Switzerland. Semi-structured individual interviews with participants were conducted on clinic premises and audio recorded. Interviews lasted between 35 and 45 minutes. Data were analysed using thematic analysis.

Living day to day with COPD, psychosocial dimension of the disease and management of complex care were the main themes identified. Patients and informal carers reported a range of psychological challenges, with feelings of guilt, discrimination and blame. Most of the participants had no knowledge of palliative care and healthcare services did not provide them with any information about palliative care approaches in advanced COPD. The reported psychological challenges may influence the relationship between patients, informal carers and healthcare professionals, adding further complexity to the management of this long-term condition. Further research is needed to explore new ways of managing complex care in advanced COPD and to define how palliative care may be included in this complex care network.

Introduction

Chronic obstructive pulmonary disease (COPD) has become a leading cause of morbidity and mortality worldwide.¹ Future projections predict that COPD will become the third leading cause of death worldwide in 2030, thus further increasing its economic and social burden.² The disease trajectory is characterised by a progressive decline in overall function, a gradual loss of patient's independence and the worsening of health-related quality of life.³ Patients experience a high symptom burden as the disease progresses.⁴ This leads to unintentional activity limitation, which may be associated with progressive social isolation and the reduction of the perceived quality of life in patients with COPD.⁵ Furthermore, this high prevalence of physical symptoms and psychological distress in advanced COPD is comparable with, or worse than the symptom burden reported in the lung cancer population.⁶

Improving the quality of life of patients and their families living with a life-limiting disease is the goal of palliative care provision.⁷ Palliative care delivery in life-threatening diseases such as COPD may improve symptom control, address multidimensional issues and coordinate care, while respecting patients' wishes and values.⁸ Although COPD is recognised as being a life-limiting condition with palliative care needs, palliative care provision is underdeveloped in this population.⁹ Patients' and informal carers' perceptions on palliative care delivery in advanced COPD were recently described in several studies. Continuity of care, reduction of care fragmentation, multidisciplinary care and networking with all involved healthcare professionals were perceived as important elements for high-quality care delivery.^{10,11}

Care delivery in this population is demanding and often complex, with multiprofessional care provision in different settings. Progressive recognition of COPD as a life-limiting condition with multidimensional needs is increasing among healthcare professionals caring for these patients and their families.¹² Informal carers provide a great extent of care for patients with advanced COPD, especially in homecare settings. This may elicit emotional distress, carer overburden and subsequently impact

the carer-patient relationship.¹³ Nonetheless, patients and informal carers' experiences in living with advanced COPD are seldom described during the disease course.¹⁴

The aims of this study were to explore the experiences of patients and informal carers in living with advanced COPD and to understand their awareness about palliative care provision in advanced COPD.

Methods

Study design

Qualitative study using semi-structured interviews, reported in accordance with the consolidated criteria for reporting qualitative research (COREQ) guidelines.¹⁵

Participants and setting

This study was conducted in a respiratory care service located in a major public teaching hospital in Southern Switzerland. Participants were selected through stratified purposive sampling in order to identify patients with advanced COPD (GOLD stages 3 and 4) and informal carers providing care for these patients. Potential participants were identified through medical records by personnel not involved in the study. The proper identification according to their disease stage was subsequently confirmed by a respiratory care physician. Participants were recruited either by mail or through trained personnel not involved in the study, prior to scheduled consultations. Patient-carer dyads were not necessary for sampling. Therefore, patients and informal carers were not prevented from study participation even if their carer (for patients) or the family member they were taking care of (for informal carers) declined to join the study. Informal carers were identified by patients as being their main informal carer and were recruited either by mail or when accompanying patients to scheduled consultations. A signed consent form was collected on the interview day. Inclusion and exclusion criteria, as listed in **Table 1**, were applied during the process. Patients were excluded if they benefitted from palliative care

provision, in order to explore their awareness about the role palliative care could play in advanced COPD.

Data collection

Individual semi-structured interviews were conducted in Italian by the first author. The interviews lasted between 30 and 45 minutes and were conducted in a conference room on clinic premises during working hours. They were digitally recorded, anonymised, transferred to a password-protected computer and transcribed verbatim in Italian. An interview guide duly created in Italian for this study ensured that the same domains were explored during each interview and the English translation is depicted in **Table 2 and 3**. Data saturation was considered to be achieved when further coding was not feasible.¹⁶ Since transcription and coding were performed after each interview, main themes were identified after the first 16 interviews. The following interviews allowed to confirm that further coding was not feasible and that new themes were not identifiable for both patients and carers.

Data analysis

The first author analysed the individual interviews using thematic analysis.¹⁷ Transcripts were analysed using a qualitative data analysis software package (NVIVO®). An inductive approach was chosen during data coding and analysis, in order to capture patients' and informal carers' experiences. The other authors supervised the coding and analytical process. A step-wise approach was adopted and transcripts were edited on MS Word. Engagement with raw data represented the first step of data analysis. Transcribed verbatim and digital recordings were read through and listened to several times to engage with the collected data. In this phase it was crucial to pay attention to what participants were saying and how they were expressing their views and experiences. In the second step of data analysis initial codes were identified. These codes were both semantic, where the code came closely out of what was said or interpretative (or latent) where what was said was interpreted. The third step of data

analysis was represented by the development of themes and subthemes, the latter defined as elements composing a theme. The development of themes and subthemes was fostered by clustering codes which enabled to identify common pattern across the collected data.¹⁸ After identification of themes and subthemes in Italian they were translated to English. The fourth step of data analysis involved reviewing identified themes and relating them to the collected data. Reflections on how collected data supported the identified themes in terms of coherence and meaningfulness in relationship to the research question helped to confirm that the identified themes represented the perceptions and experiences of patients with advanced COPD and of their informal carers. Furthermore, transcriptions were read once more to review the identified themes against the collected data.¹⁸ The fifth and sixth step of data analysis addressed the final definition of the identified themes and how to present them in the results' section.

Ethical considerations

Ethical approval was granted from both the Swiss and the Lancaster University Research Ethics Committee. The study complied with the guidelines of the Declaration of Helsinki regarding ethical principles for medical research involving human subjects.

Results

20 patients and 20 informal carers were interviewed from September 2016 to January 2020. The first ten interviews were performed between September 2016 and March 2017 as part of a pilot study, the remaining 30 interviews were performed between August 2019 and January 2020. An overview of participants' main demographic characteristics is shown in **Table 4** and **5**. 22 females and 18 males participated in the study. Median age of participants was 63 years (range 35-76 years). Patients were older than informal carers. Patient and carers' dyads were present for participant P1 and IC1, P5 and IC3, P6 and IC6, P7 and IC7, P13 and IC 12 and for P14 and IC16. Informal carers were mainly family

members, only one carer was a patient's close friend and neighbour (IC4). Participants' education level was almost equally divided between middle school and high school/university degree. Patients' mean FEV1 was 33% (range 26-45%) and mean CAT was 26.5 (range 9-36).

Three main themes emerged during analysis: living day to day with COPD, psychosocial dimension of the disease and management of complex care. An overview of the identified themes and subthemes is listed in **Appendix 1**.

1. Living day to day with COPD

Patients and informal carers described what it was like living day to day with advanced COPD or caring for a relative affected by the disease. Physical symptoms such as breathlessness, cough and fatigue were described and both patients and informal carers highlighted the impact these symptoms had on daily activities.

“When I go out, I walk for about 50 meters to the bus station...and I am already out of breath...it is getting worse day by day”. (P1)

Informal carers are unable to sleep at night as they are frequently woken by their spouses.

“He always coughs at night...and when he catches the flu...it is worse...it is difficult to sleep, even if we sleep in two separate bedrooms”. (IC2)

“I am always awake at night, the least noise...because when he is short of breath it seems that he whistles...that's very frightening...I wish he could breathe better...”. (IC14)

Daily life activities were limited and adapted to the progressive functional decline. Moreover, the need for frequent medications, such as inhalation therapy and long-term oxygen treatment further reduced patients' independence in daily living.

“Grocery shopping has become a four hours ritual, since I need to do my inhalations first and then prepare the portable oxygen which I need to take with me...and the supermarket is only 300 meters away...”. (P3)

All patients and informal carers also underlined that living with COPD also meant they needed strategies to deal with the illness, to talk about it and to be aware of the overall implications the illness had on both patients and their families.

“I try to find distractions in daily life and to enjoy myself as much as I can...I think my positive attitude helps me to face the difficulties with this respiratory problem”. (P2)

A sense of loss was described by all patients and carers in living day to day with COPD. Patients shared the loss of independence and issues of impairment as the disease progressed. They recalled all the daily life activities they were able to perform before disease progression in comparison with the limitation they experienced currently in daily life. Not only was physical impairment a topic, but they also described a reduced enjoyment in life due to an increased need for help, both from informal carers and healthcare professionals.

“When I am feeling better, I make some plans...I have a lot of things to do at home, tidy up the basement...but it doesn't work alone...I need help from my children and it is frustrating...”. (P6)

Dealing with the illness in daily life and being able to talk about it within the family and with healthcare professionals was important for all patients and carers. These aspects which emerged from the interviews and were identified as subthemes in daily living with COPD were recognised as being overlapping with the psychosocial dimension of the illness.

2. Psychosocial dimension of COPD

All patients and informal carers discussed the psychological dimension of COPD, in particular their emotions while living with or caring for a relative with COPD. Feelings of fault emerged among both patients and carers. Patients felt guilty and were ashamed of their smoking habit. Only one patient reported that she enjoyed pursuing her smoking habit. Guilt was perceived by patients towards their families, especially towards spouses and children for the way in which the effects of living with the illness impacted more widely on the couple/family relationship.

“I feel guilty because I realise that with my breathlessness I am limited with all my activities...I loved hiking in the mountains with my wife, but this is now impossible for us”. (P5)

This sense of guilt was openly discussed in relation to taking responsibility for acquiring the disease, nonetheless three patients tried to implicate other causes for the illness, so that smoking was one of several factors concurring to the development of COPD.

“A smoker knows that it is harmful...every excess is harmful, but why not talking about air pollution? This is harmful too and there is nothing to do about it”. (P7)

At the same time, all informal carers blamed patients for their smoking habits leading to a “self-inflicted” disease, which influenced both patients and family lives. Furthermore, informal carers blamed patients for their inability to stop this habit.

“...but if he would stop smoking, he may be able to keep 40% of his lung function...but nothing, he keeps smoking...”. (IC19)

The latter aspect emerged in spouses who were formerly smokers and who were able to stop on their own. They felt their relative had a lack of commitment and willpower in stopping the habit.

“...so I quit...well, we promised each other to stop, but...he didn't keep his promise...”. (IC3)

Patients were aware that carers blamed them for not being able to stop their habit and this increased the sense of guilt. An unspoken mutual understanding about this emotional aspect was apparent, nonetheless it was not openly discussed within the patient-carer relationship, in order to maintain a quiet living.

“...I know she (my wife) blames me for this situation...she doesn't talk to me directly about it, but sometimes her comments are quite clear about it...especially when she discusses our current situation with others...”. (P8)

“He is responsible for our situation...but why talk about it...he knows...and talking about it just makes daily living more complicated...”. (IC8)

Furthermore, all patients blamed healthcare professionals for feeling discriminated against because of their illness, which was described at different time points in their disease trajectory. They perceived that they were stigmatised because of their “addiction” and that COPD had a negative connotation among healthcare professionals because of the direct link between smoking and disease. Nonetheless, patients did not report low quality of care because of this sense of discrimination, but they perceived that healthcare professionals focused greatly on stopping their smoking habit and reiterated that during every visit, both planned and during exacerbations. Therefore, patients felt that issues they considered to be important from their perspective were not discussed with professional carers.

“...because there is already a path...it is written “smoker” and you are branded”. (P12)

“COPD has a negative feature...the same as for instance for AIDS...you don't know what it is but when you say AIDS you are already dead...”. (P2)

Feeling anxious was described as an important emotional aspect, both by patients and carers. Patients experienced anxiety in relationship with breathlessness, especially during an acute episode of shortness of breath or during an exacerbation. They perceived that both symptoms influenced each other further with the disease progression.

“...because I already had dyspnea episodes and I was frightened the first time...after that I really felt anxious with every episode of even slight shortness of breath...”. (P13)

Moreover, all patients and informal carers described their fears related to the disease itself and to the progressive physical decline. Fears of suffering and death were expressed by both patients and carers. Additionally, patients expressed their fear about what they could expect from the illness progression and about getting worse or being diagnosed with what they described as a “far more serious disease” such as cancer.

“...I don't fight death, because it is useless to fight a thing which is already decided when you are born...it is fate...nonetheless I am afraid of suffering...pain, breathlessness...all these are frightening”. (P11)

Carers, particularly spouses and children, experienced a sense of loneliness and social isolation. They lived the illness together with their relatives and perceived the impairment as their own. Socialisation eventually became impossible in view of the declining health status of patients.

“We always had a lot of friends and family in our home...this is the past...he doesn't want anyone at home...it is so sad and I feel lonely...”. (IC6)

Furthermore, carers perceived a loss of ability to care for their relatives. This was described as a permanent feeling of being inadequate to care for their spouse, father or close friend. They questioned

their ability as a carer with further disease progression, increased symptom burden and physical impairment.

“If she gets breathless, I am getting anxious and distressed...I really ask myself if I am the right person to look after her...”. (IC4)

This sense of being inadequate to care for patients with advanced COPD led to anxiety and emotional distress in informal carers. These feelings had an impact on the daily management, thus increasing care complexity in advanced disease.

3. Management of complex care in COPD

All patients and informal carers recognised that care was complex and could be fragmented which impacted their quality of life. They perceived the need to create a structured care network in which all healthcare professionals caring for patients were involved. According to their experiences this would allow a shared care plan through continuous communication and the integration of patients and relatives in decision making. Furthermore, carers expressed their belief in better care for their relatives through partial relief of the carer burden.

“When everything got in place...it took some time...but when it got off...the care for my father...I felt relieved”. (IC5)

Patients and carers asked for transparency regarding diagnosis and its possible impact on daily living. Furthermore, patients experienced a feeling of insufficient understanding for their situation from several healthcare professionals, in particular while discussing it with their respiratory physician. They expressed the need for more time during consultations in order to ask questions about the illness.

“Well, knowing the people, what they have on their mind...I would like them to be understanding towards my situation”. (P17)

Moreover, patients and carers expressed their need for healthcare professionals to understand their multidimensional needs, while discussing a disease management which integrates all aspects considered important by patients and their carers. It emerged from their experiences that not all healthcare professionals were “so open-minded” to take such a holistic approach in caring for patients with advanced COPD and their families.

Participants were specifically asked about palliative care and its role in the disease trajectory of patients with advanced COPD. Most of them had no knowledge of palliative care and the participants who were previously informed about palliative care gathered this information through relatives and friends who shared their experiences with palliative care services. None of the participants reported that healthcare services provided them with information about palliative care approaches in advanced COPD. When shown palliative care definition (WHO definition), they expressed that this was the type of care they believed should be provided for patients with advanced COPD. Holistic and multidimensional care was felt as important to support patients and their care network. Additionally, addressing social and financial related issues and promoting and respecting patients’ values and wishes was considered to be equally important. Both patients and carers emphasised lacking this type of care delivery in advanced COPD.

“...I think it would be important to discuss other aspects as just the ones related to the disease...what do I want and what do I need to make my life worth living...”. (P9)

“...maybe to teach her how to manage a situation...with breathlessness or anxiety, what to do and how...I think it could be really useful...”. (IC4)

“I think palliative care should be involved in any care setting...at home especially...it gives you support in need and helps you to avoid suffering”. (IC5)

Sharing experiences with other people with COPD and their carers (defined as peers) was perceived as important for both patients and carers. Patients felt that they could possibly talk with peers about living with the illness and develop better coping strategies. At the same time, they expressed it was important to raise awareness amongst healthcare professionals about the lived experience in COPD from the patients' point of view.

"...and then I met other people, with the same illness...one had a lung emphysema and a tumour...it was helpful to talk about our situation...you share your moments with them". (P3)

Carers felt that sharing experiences with others living in a similar situation could help to improve their quality of care giving. The creation of support groups for informal carers was also raised by interviewees. Carers shared the view that such groups could be helpful for sharing practical advice on the availability of support for patients and families, but they could also create emotional bonds which may help to deal with the progressive decline of their relatives. They emphasised the need for healthcare professionals to initiate the development of such self-help group, which are currently lacking.

Discussion

This study illustrates the experiences of patients and their informal carers in living with advanced COPD. Some of the reported limitations related to disease progression, such as decline of daily life activities and social isolation, have been previously been described.^{13,19-23} However, this paper highlights experiences described by patients and informal carers such psychological challenges, with feelings of guilt, discrimination and blame which appear to be underreported in previously published studies.²⁴⁻²⁶

Patients expressed feelings of guilt and shame about their smoking habit with respect to their family. Being responsible for acquiring the disease was openly discussed during the interviews, but rarely

acknowledged within the patient-carer relationship, even if there was a major impact on daily living from the disease for both patients and their informal carers. Conversely, carers blamed patients for their smoking habit and for the inability to quit. They reported that this “self-inflicted” disease led to a radical change in their lives, with a sense of loss of social activities and isolation. This important aspect needs to be deeply considered, as it could have a negative impact on the patient-carer relationship, which is essential for care delivery in this population.¹³

Patients reported the perception of stigma and discrimination by healthcare professionals because of their smoking habit. Ceasing to smoke was always addressed during consultations and patients felt that time was lacking for discussions about other issues they considered to be important for their daily life. Nonetheless, patients were satisfied with the quality of care they received along the disease trajectory. This contrasts with prior findings where patients perceived negative attitudes from healthcare professionals, especially if they did not manage to quit their smoking habit.²⁴ Improving communication skills on addressing smoking behaviour in COPD patients may reduce the perception of discrimination and strengthen the therapeutic relationship.

Management of complex care emerged as an important issue among patients and informal carers. The impact on carers of providing support for patients with advanced COPD was considered as important and challenging. Feeling inadequate to care for their relatives and question their ability as a carer with disease progression was well described by interviewed informal carers and is similarly reported in other long-term conditions, such as heart failure.²⁷⁻²⁸ These perceptions may reflect the need for the development of self-help groups for this population, following neurodegenerative diseases’ models. These groups can provide carers with practical information and help sharing the experience of the disease progression. Furthermore, they may reduce the feeling of social isolation of both patients and informal carers.²⁹

As emphasised by previous studies, better information about the disease and its impact on daily life was requested by both patients and carers.^{22-23,30} The fragmentation of care reported during interviews could be addressed by the implementation of a structured care network with a clear leadership coordinating all services which provide care for a patient.³¹ Palliative care services are designed to deliver multiprofessional care, while managing multidimensional complexity and they could play a role in the development of a care network for patients with advanced COPD.³² Awareness about palliative care and its role in care delivery of patients with advanced COPD was lacking. None of the participants reported that healthcare services provided them with information about palliative care, the ones who were informed gathered their knowledge through their social network. Nonetheless, as similarly reported in previous studies, they were receptive to components of palliative care integration, such as multidimensional care and promoting and respecting patients' values.²³

Potential study limitations need to be acknowledged. The relatively small study sample (20 patients, 20 carers) might be prone to provide an incomplete insight on patients and carers' experiences. Data saturation was reached after 16 interviews, nonetheless 24 further interviews were performed to assure that further coding was not feasible and that new themes were not identifiable for both patients and carers. Interviews were conducted in a single service in Southern Switzerland where local and regional peculiarities need to be considered and which might prevent a broader generalizability of findings to other countries. Nonetheless, some of the identified themes were also reported in previously published studies in broader contexts.^{13,22, 33}

Conclusion

This study explored the experiences of patients and informal carers living with advanced COPD. Our findings confirmed the high impact of the illness on daily living. Furthermore, a range of psychological challenges along the disease trajectory, with feelings of guilt, discrimination and blame was reported. These perceptions may influence the relationship between patients, informal carers and healthcare

professionals, adding further complexity to the management of this long-term condition. Further research is needed to explore new ways of managing complex care in advanced COPD and to define how palliative care may be included in this complex care network.

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Table 1: Inclusion and exclusion criteria for patients and informal carers

Inclusion criteria patients	Exclusion criteria patients
<ul style="list-style-type: none">• Adults (> 18 years old)• Formally diagnosed (spirometry) and documented (in medical chart) advanced COPD (GOLD classification 3-4)• Outpatients in the respiratory care service• Fluent in Italian• Competent and willing to sign informed consent sheet	<ul style="list-style-type: none">• Inability to join consultations as outpatient• Hospitalisation at the time of recruitment• Palliative care recipients (as outlined in medical charts)• Concurrent oncological disease
Inclusion criteria informal carers	Exclusion criteria informal carers
<ul style="list-style-type: none">• Adults (> 18 years old)• Identified by patients with COPD as relative/friend who provides care at home• Fluent in Italian• Competent and willing to sign informed consent sheet	<ul style="list-style-type: none">• Inability to join consultations as informal carer

Table 2: Thematic interview guide for semi-structured interviews with patients

Symptom control
<ul style="list-style-type: none">• What are the most bothering symptoms right now?• What are the strategies you adopt to control these symptoms?• Do you benefit from the prescribed treatments? Do they help in controlling your symptoms?
Experiences with advanced COPD
<ul style="list-style-type: none">• What do you know about your illness?• Can you tell me for how long have you been living with your illness?• Does COPD limit your daily life activities?• How would you judge your current quality of life?• Do you often think about the future?
Current care provision
<ul style="list-style-type: none">• How would you describe your current care provision?• What would you like to change in your current care provision?• What do you expect from your healthcare professionals?
Palliative care provision
<ul style="list-style-type: none">• Have you ever heard about supportive or palliative care?• Now that I have explained the definition of palliative care to you, can you tell me what you think about this type of care provision?• Do you think palliative care may be useful for you?

Table 3: Thematic interview guide for semi-structured interviews with informal carers

Symptom control
<ul style="list-style-type: none">• What are the most frightening symptoms you observe in your husband/wife/father/mother?• What are the strategies you adopt with your husband/wife/father/mother to control these symptoms?
Experiences with advanced COPD
<ul style="list-style-type: none">• What do you know about advanced COPD?• Can you tell me for how long has your husband/wife/father/mother been living with COPD?• How does COPD affect your life as an informal carer?• How would you judge your current quality of life?• Do you often think about the future?
Current care provision
<ul style="list-style-type: none">• How would you describe the current care provision of your husband/wife/father/mother?• What would you like to change in this current care provision?• What do you expect from healthcare professionals caring for your husband/wife/father/mother?
Palliative care provision
<ul style="list-style-type: none">• Have you ever heard about supportive or palliative care?• Now that I have explained its definition to you, can you tell me what you think about this type of care provision?• Do you think palliative care may be useful for your husband/wife/father/mother?

Table 4: Main demographic characteristics of interviewed patients

Participant	Age (years)	Gender	Educational level	Smoking status	Pack-years	FEV1	Exacerbations per year	GOLD classification	mMRC Dyspnea Scale	COPD Assessment Test (CAT)
Patients										
P1	65	Male	Primary school	Former smoker	80 py	28%	4	GOLD 4D	Grade 4	30
P2	63	Female	Middle school	Current smoker	40 py	45%	1	GOLD 3A	Grade 1	9
P3	72	Male	High school	Former smoker	60 py	28%	2	GOLD 4D	Grade 3	25
P4	76	Female	University	Current smoker	50 py	36%	1	GOLD 3B	Grade 2	20
P5	70	Male	Middle school	Current smoker	80 py	40%	2	GOLD 3D	Grade 3	26
P6	71	Male	University	Former smoker	60 py	28%	3	GOLD 4D	Grade 3	28
P7	73	Female	High school	Current smoker	70 py	29%	3	GOLD 4D	Grade 3	25
P8	68	Male	Middle school	Current smoker	60 py	28%	1	GOLD 4B	Grade 4	35
P9	69	Male	Middle school	Former smoker	40 py	35%	3	GOLD 3D	Grade 3	26
P10	74	Male	Primary school	Former smoker	80 py	27%	3	GOLD 4D	Grade 4	33
P11	68	Male	High school	Current smoker	50 py	26%	4	GOLD 4D	Grade 3	30
P12	65	Male	University	Former smoker	50 py	28%	4	GOLD 4D	Grade 3	29
P13	72	Female	High school	Current smoker	45 py	37%	2	GOLD 3D	Grade 3	22
P14	70	Female	Middle school	Current smoker	35 py	40%	1	GOLD 3B	Grade 2	21
P15	66	Male	Middle school	Current smoker	60 py	27%	3	GOLD 4D	Grade 4	34
P16	65	Male	High school	Former smoker	40 py	38%	1	GOLD 3B	Grade 2	20
P17	69	Male	High school	Former smoker	45 py	28%	3	GOLD 4D	Grade 3	30
P18	67	Female	Middle school	Current smoker	40 py	42%	2	GOLD 3D	Grade 3	28
P19	68	Male	Middle school	Former smoker	30 py	44%	1	GOLD 3B	Grade 2	23
P20	70	Male	Primary school	Current smoker	80 py	26%	4	GOLD 4D	Grade 4	36

Table 5: Main demographic characteristics of interviewed informal carers

Participant	Age (years)	Gender	Educational level	Relationship with patients	Smoking status	Pack-years
Informal carers						
IC1	59	Female	Primary school	Wife of P1	Never smoker	--
IC2	76	Female	Middle school	Wife	Never smoker	--
IC3	65	Female	Middle school	Wife of P5	Former smoker	20 py
IC4	47	Female	Middle school	Close friend	Never smoker	--
IC5	39	Female	High school	Daughter	Never smoker	--
IC6	65	Female	High school	Wife of P6	Never smoker	--
IC7	42	Female	Middle school	Niece of P7	Current smoker	20 py
IC8	64	Female	Middle school	Wife	Former smoker	25 py
IC9	38	Male	University	Son	Never smoker	--
IC10	35	Female	University	Daughter	Never smoker	--
IC11	62	Female	High school	Wife	Former smoker	40 py
IC12	63	Male	Middle school	Husband of P13	Current smoker	50 py
IC13	41	Male	High school	Son	Never smoker	--
IC14	72	Female	Middle school	Wife	Former smoker	30 py
IC15	71	Female	Middle school	Sister	Never smoker	--
IC16	37	Female	University	Daughter of P14	Never smoker	--
IC17	70	Female	Middle school	Wife	Current smoker	40 py
IC18	59	Male	University	Husband	Current smoker	45 py
IC19	64	Female	Middle school	Wife	Never smoker	--
IC20	61	Female	Middle school	Wife	Former smoker	20 py