

The impact of Chronic cough: a cross sectional European survey.

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Introduction

The prevalence of chronic cough has been estimated as affecting 11-13% of the population.[1-4] Chronic cough is associated with significant physical and psychological morbidity.[5, 6] Adverse physical symptoms associated with cough include syncope, incontinence, chest pain, headaches and sore throat. Depression, anxiety and social embarrassment are also common.[5, 7, 8] The impact of chronic cough has largely been investigated in patients attending specialist cough clinics [5, 6, 9]. Few studies have investigated the impact of chronic cough in patients based in the community. The aim of this study, in collaboration with the European Lung Foundation (ELF), was to investigate the impact of chronic cough from the patients' perspective in a wide range of European countries. An internet based survey was developed to investigate the impact, medical consultations, diagnoses, treatments and needs of patients with chronic cough.

Methods

Subjects

Adults with chronic cough (duration > 8 weeks) of any cause were recruited using an internet-based survey. Exclusion criteria were: acute and sub-acute cough, age <18 years and non-European country of residence. A patient information sheet was provided online on the ELF website. Participants who selected to complete the online survey were considered to have given implied consent. Secondary anonymised data from the survey was analysed.

Survey Development

Phase 1 – Item generation

A preliminary survey (21 items) was developed following a review of the chronic cough health related quality-of-life (QoL) literature and published surveys of chronic cough. The survey was also reviewed and discussed within the European Respiratory Society (ERS) Chronic cough Taskforce (15 respiratory physicians from nine countries), a multidisciplinary team (respiratory physician and physiotherapists, Kings College Hospital) and the ELF. The survey contained both open-ended and closed questions with response scales.

Phase 2 – Survey refinement

The survey was adapted for use on the internet and reduced to 17 items in response to feedback received during the item generation phase. The items were grouped into five categories: “About your cough,” “How are you affected by your cough?” “Diagnosis of your cough,” “Treatment of your cough” and “Support for patients with cough” (Appendix A).

Phase 3 – Translation of survey

The survey was translated by Web-Translations (Leeds, UK). Forward-back translation methodology was used by native speakers to ensure accuracy. The back translated survey was checked by the original author (SSB) for accuracy and differences were reconciled during a harmonisation process. The survey was translated into 12 languages: English, German, French, Spanish, Greek, Romanian, Lithuanian, Swedish, Italian, Bulgarian, Polish and Russian.

Internet survey

The survey was launched by the ELF on their website www.european-lung-foundation.org (website has now changed to www.europeanlung.org) using a Survey Monkey survey package. Google AdWords was used to advertise the survey on Google searches. This used keywords or search terms entered into a Google search website to return the cough survey in the Google results page and advertisement sidebar. The keywords set for this survey were “chronic cough,” “cough survey,” “a cough that won’t go away” and “can lung disease make you cough”. These key words were identified by the ELF, following review of the literature and online resources for cough. Keywords were translated and applied for each survey language. The survey was promoted by the ELF by developing advertisement posters in all survey languages with dissemination to all ERS members (>10,000) and ELF patient organisation network (>160 organisations). The posters were available on the ELF website to download. The survey was also promoted in the ELF monthly newsletter and via social media (Twitter and Facebook).

Analysis

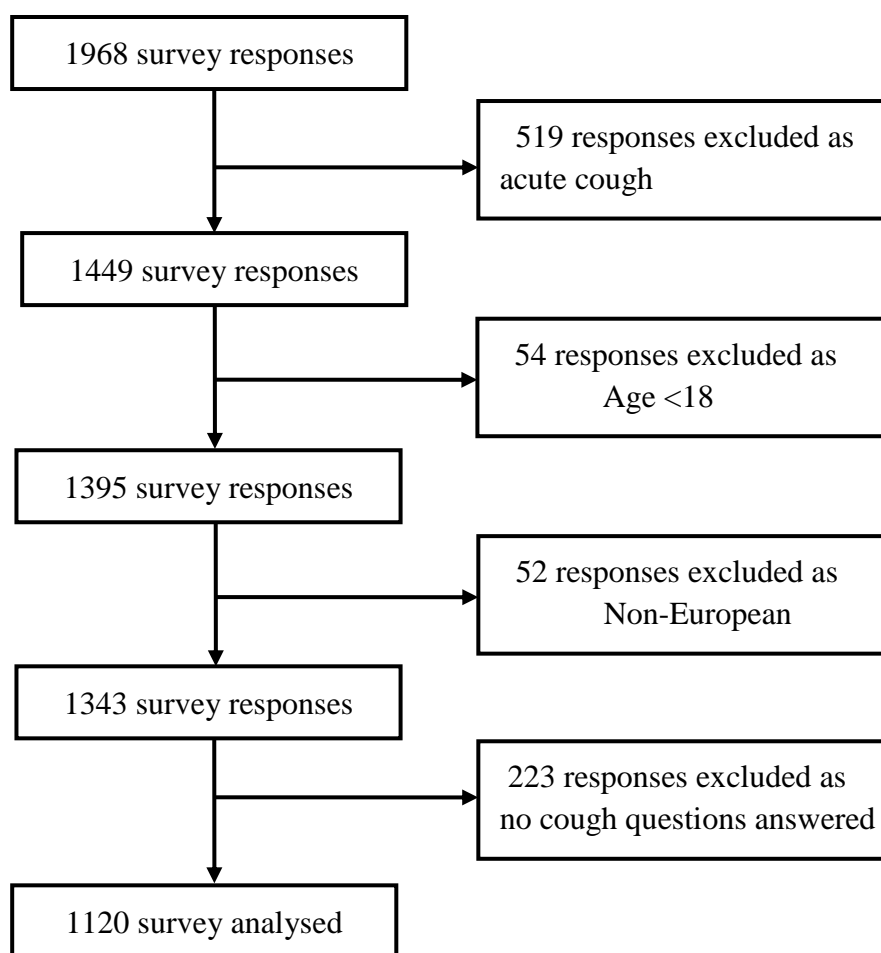
Count data were expressed as frequencies and percentages of the total number of participants responding to each question. The data were analysed as a whole sample and then as sub-groups according to country of residence (countries with >50 responders) and gender. Categorical data for “the impact of cough” questions (questions 5-8, appendix A) were summarised as binary variables to enable calculation of the proportions of participants with the symptom. Open questions (questions 2, 16, 19 and 20; Appendix A) were analysed by frequency content analysis. Preliminary categories were further refined to generate consolidated

themes. The data generated by questions relating to further information and support were merged for analysis (questions 19 and 20).

Results

The survey was available between January 2012 and April 2013. 1,968 participants responded and completed the survey; 1,120 met the inclusion criteria. The reasons for excluding participants are stated in Figure 1.

Figure 1. Flowchart of survey responses and exclusions.



Data presented as number of survey responses.

Sixty-seven percent of respondents were female, the mean age of respondents was 51 years (SD 15, range 18-87) and 83% were non-smokers (participant demographics are presented in Table 1).

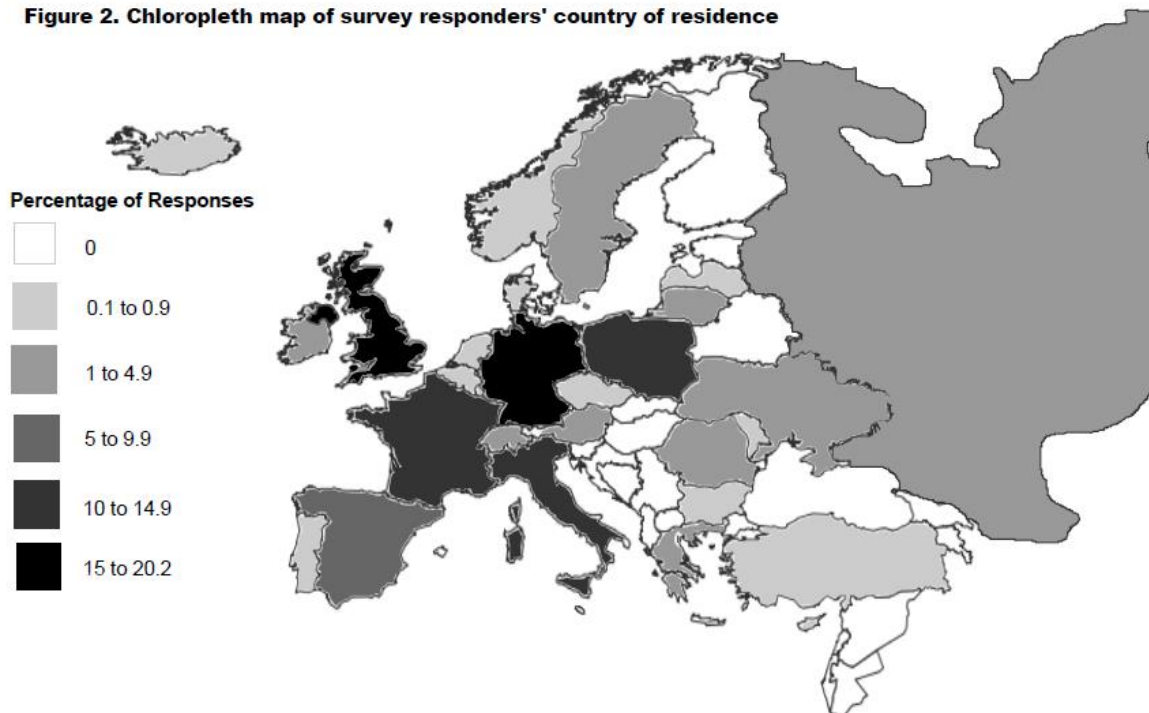
Table 1: Respondents Demographics

Subjects (n)		1120	
Age (years)	All	51	(15)
	Male	51	(17)
	Female	51	(14)
Female n (%)		489	(67)
Ethnicity n (%)			
	White Caucasian	540	(90)
	Black Caribbean	3	(0.5)
	Black African	3	(0.5)
	East Asian e.g. Japan, China	3	(0.5)
	South Asian e.g. India, Bangladesh	4	(0.7)
	Mixed	5	(0.8)
	Other	42	(7)
Current smokers n (%)		185	(17)
Seen a doctor regarding cough at least once n (%)		1043	(93)
Seen a doctor regarding cough ≥ 3 times n (%)		807	(72)
Attended specialist cough clinic (%)		135	(13)

Data presented as mean (standard deviation) unless otherwise stated

The respondents resided in 29 European countries (Figure 2). The countries with the five highest response rates were United Kingdom (UK) (n=136, 20%), Germany (n=114, 18%), France (n= 76, 11%), Italy (n= 70, 10%) and Poland (n= 67, 10%).

Figure 2. Choropleth map of survey responders' country of residence

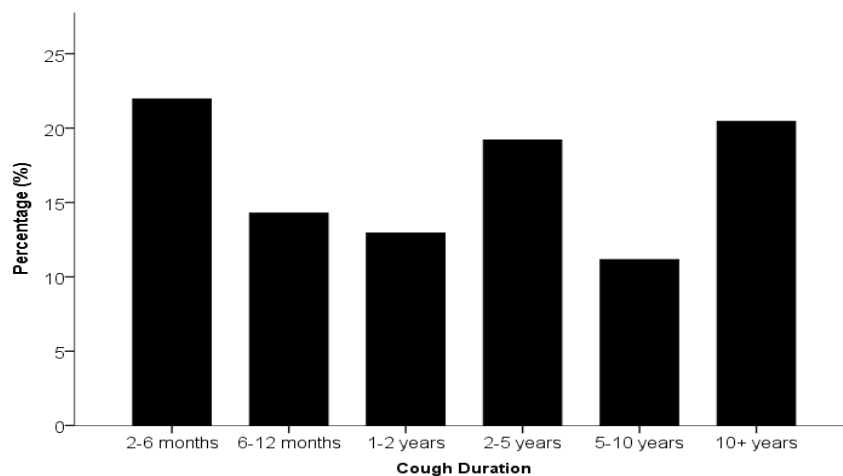


Data presented as percentage of responses

Diagnosis

Median duration of cough was between 2-5 years. There were two peaks of cough duration; twenty-two percent, reported an early chronic cough (3-6month duration) and a similar number, twenty percent reported a cough duration of 10 or more years (Figure 3).

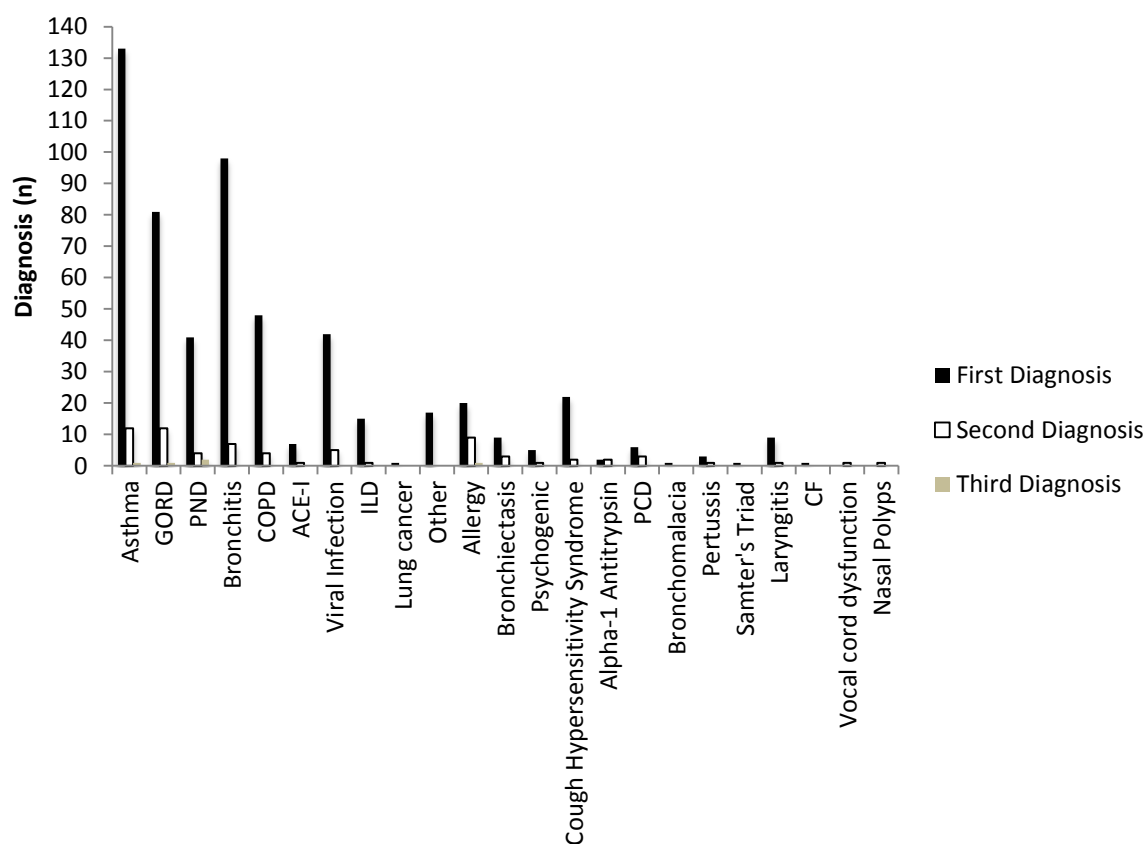
Figure 3. Cough Duration of Survey Respondents.



Data presented as percentage of survey respondents.

Fifty-three percent (n=562) of respondents reported they had been given a diagnosis for their cough (Figure 4). Seven percent of respondents who had been given a diagnosis had been given two or more diagnoses. Asthma was the most common diagnosis reported (23%; Figure 4).

Figure 4. Cough Diagnoses of Survey Respondents.



Data presented as number of survey respondents. GORD – Gastro-oesophageal reflux; PND – Post-nasal drip; COPD – Chronic Obstructive Respiratory Disease; ACE-I – Angiotensin-converting-enzyme Inhibitor; ILD – Interstitial Lung Disease; Other – includes non-disclosed diagnoses of cough; PCD – Primary Ciliary dyskinesia. First, second and third diagnoses were defined as the first, second and third diagnoses listed by survey respondents in response to Survey Question 10.

Impact of chronic cough

Ninety-six percent (n=1,055) of responders reported that their cough affected their QoL. Eighty-one percent (n=890) reported that their cough affected the activities they liked to do. Ninety-one percent (n=1,000) reported feeling fed-up and depressed because of their cough and 94% (n=1,030) reported that their cough disturbed or worried their family and friends. The impact of cough was consistent across the top five countries of residence for the respondents (Table 2).

Table 2: Impact of chronic cough (top five response countries).

Country	Negative Impact on activities	Feeling fed up or depressed	Negative Impact on quality of life	Worrying or disturbing family or friends
UK	87 (80-91)	94 (89-97)	96 (91-98)	98 (94-99)
Germany	85 (77-90)	98 (94-100)	98 (94-100)	90 (83-94)
France	75 (64-83)	92 (84-96)	97 (91-99)	95 (87-98)
Italy	74 (63-83)	90 (81-95)	96 (88-99)	94 (86-98)
Poland	90 (80-95)	90 (80-95)	97 (90-99)	99 (92-100)

Data presented as % of responders (95% Confidence Intervals)

There were significant gender differences in the limitation of activities due to cough; a significantly higher proportion of women (87%; Confidence Interval (CI) 84-90%) than men (77%; 95 CI 72-82%) reported limitations (difference in proportion 10%; CI 4-16%). More women (94%; CI 92-96%) than men (90%; CI 85-93%) reported feeling fed up or depressed due to their cough (difference in proportion 5%; 95 CI 0-9%). No significant differences in population proportions were found between gender for impact on QoL or on family and friends.

Management and treatment of chronic cough

The majority of respondents had seen a doctor about their cough (Table 1). Seventy-two percent of participants had seen a doctor ≥ 3 times in relation to their cough. Thirteen percent reported that they had attended a specialist cough clinic. Only 30% of respondents felt their doctor had dealt with their cough thoroughly. Participants were asked in an open-ended question why they had first consulted their doctor. This question generated seven themes: the characteristics of the cough (n=422), physical symptoms associated with cough (n=380), possible viral infection symptoms (n=140), psychological symptoms associated with cough (n=88), to consult a doctor about existing respiratory or other health condition (n=80), social symptoms associated with cough (n=76) and for diagnosis/assessment and treatment for the cough (n=31), (Online Appendix B). Some examples of quotations from respondents are listed in Online Appendix C.

Most respondents reported limited (57%) or no (36%) effectiveness of medications they had tried for cough. Only 7% reported that medications they had tried for their cough were effective. Medications found helpful for their cough were reported by 222 responders (Question 16 – open ended question; see Table 3). Sixty-nine percent of respondents reported over-the-counter medications were not effective.

Table 31: Effective medications for cough reported by respondents

Medication	%
Corticosteroids (oral and inhaled)	37
Antibiotics	23
Bronchodilators	21
Over the counter cough medications	17
Gastroesophageal Reflux medications (proton-pump inhibitor (PPI), non-PPI and unspecified reflux medications)	10
Antihistamine/anti-allergy medications	7
Opiates	6
Mucolytics (tablets and nebulised)	6
Unspecified asthma treatment	4
Nasal sprays (decongestant and corticosteroids)	4
Homeopathy/herbal medications	4
Leukotriene antagonists	3
Amitriptyline	0.5
Bronchovaxon (immunostimulant, Bacterial Lysate)	0.5
NSAID	0.5
Gabapentin	0.5
Other	1

Data presented as percentage of the number of respondents who reported 1 or more effective medications. 73% of respondents listed one medication only, 19% listed two medications and 8% listed ≥ 3 medications.

Information and support

Eighty-eight percent of respondents reported that they would like more information on chronic cough to be available and 78% reported that they would like to receive more information about the ERS/ELF Chronic cough Task Force. The open-ended questions concerning further information and support needs of the respondents generated 20 themes (Table 4). The two most common themes were the need for further patient information relating to the treatment and on causes of cough. Examples of quotations from respondents requesting further information and support are listed in Online Appendix D.

Table 4: Information requested by respondents: a qualitative analysis

Themes	N (Total = 991)
Treatment	308
Causes	127
Self-help and alternative therapies	103
General information in a variety of formats	95
Better understanding, awareness and support from doctors	74
Assessment	68
Information on access to specialist cough clinics	65
Where to get help	33
Information on cough related symptoms	20
Further research and sharing of knowledge between specialists	19
Cough prevention	18
Better public awareness of chronic cough	17
Being able to liaise with other people who suffer with chronic cough	13
Psychological support	11
Information on triggers for cough	6
Why chronic cough reoccurs	4
Information on how to stop smoking	4
Information on prognosis and long term effects of chronic cough	2
Information on types of chronic cough	2
Definition of chronic cough	2

Data presented as number of responses (n) for each theme.

Discussion

This community-based survey investigated the impact of chronic cough in a large number of participants living in 29 European countries. The demographics of respondents to this survey were consistent with previous studies of chronic cough that report a middle aged, female predominance.[10-13] There was an adverse impact of cough on health-related QoL in most respondents, which was consistent across the top five response countries. The impact on activities was more significant in females compared to males. Most participants reported that their doctor had not 'dealt with their cough thoroughly' and that medications were largely ineffective.

This survey has highlighted the significant adverse impact of chronic cough to the individual. The respondents had consulted their physician for a wide range of reasons, such as the severity of cough, adverse physical and psychological symptoms associated with cough and the social impact. The effect on health-related QoL was consistent with previous studies conducted in specialist Cough Clinics by French et al[9] and Birring et al.[6] In contrast to French et al[14], a gender difference was not found in the impact on health-related QoL. This may be because we did not use validated questionnaires such as the cough-specific QoL questionnaire (CQLQ)[15] and the Leicester cough questionnaire (LCQ)[6] to assess health-related QoL. Most respondents also reported feeling 'fed up or depressed' because of their cough. This finding is consistent with those of Dicipingaitis et al[8] and McGarvey et al[7], who also reported significant depressive symptomatology in up to 50% of participants. The prevalence of depressive symptoms in our study was greater than this (91%), though again this was not measured by validated questionnaires, hence the severity of these reported symptoms in our respondents is unknown.

Only 53% of the survey respondents had been given a suggested diagnosis for their cough. This was despite the respondents having consulted their doctor on multiple occasions. However, it is possible that some patients were still undergoing investigations for the cause of their cough and only 13% of our participants had been assessed in specialist cough clinics. These factors may have contributed to the high prevalence of unexplained chronic cough. Only 30% of participants felt that their doctor had dealt with their cough thoroughly. When a diagnosis was suggested, the most common cause was asthma (23%). Gastro-oesophageal reflux disease and upper airway cough syndrome (post-nasal drip) were also common causes, consistent with previous studies of cough that investigated subjects with the Anatomic Diagnostic Protocol as recommended by chronic cough guidelines [12, 16-18]. As expected, some respondents reported multiple causes of cough.

Our study findings suggest that there is room for improvement in the management of patients with chronic cough. One approach is to increase awareness of this condition, and improve the implementation of chronic cough management guidelines in both primary and secondary care. Another approach could be to improve patient access to specialist cough clinics, by increasing the number of such clinics. A key finding reported by participants was that their medications, including over-the-counter medications, were ineffective. The reasons why other prescribed and over-the-counter medications were ineffective are unclear, and was beyond the scope of this study. Inadequate assessment of patients, dose/duration and non-compliance of medications and misdiagnosis could all be potential explanations[16, 17]. The reasons for treatment failure warrant further investigation.

A novel internet-based survey was used in this study to investigate the impact of chronic cough. This method was simple to set up, low-cost and one that provided data output in an electronic format that was ready to analyse. It also facilitated the recruitment of participants from across Europe. The use of the internet did not inhibit elderly participants; the age range of our study was 18-87 years. Few surveys have specifically assessed the impact of chronic cough in detail. Everett et al[19] surveyed 373 subjects with chronic cough in the community based in the UK that responded initially to a radio broadcast. Everett et al[19] also found that chronic cough was associated with a significant adverse impact on physical, psychological and social wellbeing of subjects. The strength of our study in contrast to Everett et al[19] was a larger sample size of participants with chronic cough, recruitment from 29 European countries and the additional capture of qualitative data (for example, participants' views on information and support for cough). Fujimara et al[20] surveyed 232 participants with chronic cough registered with a research company via e-mail. The recruitment of volunteers from a research company database is likely to have introduced a selection bias. Seventy-four percent of participants were male, which is in sharp contrast to most studies of chronic cough, which report a female predominance. Forty-four per cent of participants had not consulted their doctor regarding their cough, and 75% were satisfied with over-the-counter cough medications. This reflects the high number of participants with acute and sub-acute cough in their study. Cough, however, was associated with significant psycho-social impact on the subject, and females were more affected than males. Ford et al[2] identified 481 participants with chronic cough in a survey of a community based in Yorkshire, UK. The cough was considered severe in approximately half of these subjects based on the disruption to activities of daily living. However, this study did

not report the psychosocial impact, access to specialist care or treatments used for cough. Adams et al[21] identified 611 participants with chronic cough in a survey of a community based in Adelaide, Australia. Chronic dry cough was more common in participants who were male, current smokers and elderly. Cough was associated with significant psychological morbidity and impairment in health-related QoL, but this study also did not investigate the access to specialist care, treatments and information/support for participants.

There are a number of limitations with this study. Validated health-related QoL, activity or depression questionnaires were not used. We used a small selection of questions derived from literature review of health-related QoL literature and multi-disciplinary discussion. This was to keep the survey brief, and therefore encourage completion by participants. A significant number of respondents were excluded as they did not answer any of the cough-related questions. This may have been minimised by using a shorter questionnaire. The diagnoses and medications were not verified by checking medical records, as this was not feasible in this study. The use of the internet to recruit participants seeking medical advice may have led to bias, although the wide age range of our participants and a clinical phenotype consistent with previous studies of chronic cough suggests that this bias may not have been as much as expected[10-13]. Studies of the general population, perhaps by telephone, would minimise selection bias but are likely to be costly and unfeasible. The recruitment of participants is likely to have been greater if we had used a commercial Google search strategy, for example a featured advertisement, rather than the Google AdWords account. The use of other search engines and strategies may have increased recruitment of subjects. Our data does however suggest that the internet has the potential to recruit a large number of participants for

survey-based research. Our survey focused on exploring the impact of chronic cough however acute cough is also known to cause a significant impact on quality of life .[22] Future studies might explore usefully the impact of acute cough across Europe and serve to allow comparison with the findings of this present study.

In conclusion, chronic cough was associated with a significant impact on their daily activities and health-related QoL in this European study. Cough was undiagnosed in 47% of respondents. The majority of respondents said that they would like further information, support and access to specialist cough clinics. This suggests that much more work needs to be done to promote awareness of this condition, implement clinical guidelines and improve access to specialist care. This is best achieved in collaboration with patient and healthcare professional societies, such as the ELF and the ERS.

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Conflict of Interest

Authors SC, RG, AD, CB, SM, PP, SB declare that they have no conflict of interest. Author AP has received research grants from National Institute of Health Research and Pneumacare, he also received educational support from Allergan Limited, Biometrics Limited and GlaxoSmithKline. Author AM has received research grants from Boehringer Ingelheim, Cheisi Pharma, Novartis Pharmaceuticals, Orion Pharma UK, Procter & Gamble Health Sciences, Pfizer, Pharmaxis, Profile Pharma, MPEX Pharmaceuticals, PPD Development, Almirall, Seekacure, Philips Home Healthcare Solutions, Glenmark, Harrison Clinical Research, Janssen, Gilead, Bayer, Astrazeneca, Genentech, Bionoria, PRA International, GlaxoSmithKline, Allianz Global, Guangzhou Institute of Respiratory Disease, Cardiff Chest Federation, British Pharmacological Society, Italian Society of Respiratory Medicine, Drug Information Association, SRxA USA, Association of Inhalation Toxicologists, Ardmore Healthcare Limited, Actelion, Hellenic Society of Respiratory and Occupational Chest Diseases, Primary Care respiratory Society UK, TREAT Education USA, National Health and Lung Institute.

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Online Appendix A: Chronic Cough Survey

1. How long have you had your cough?

(<3 weeks, 3-8 weeks, 2-6 months, 6-12 months, 1-2 years, 2-5 years, 5-10 years, 10+ years)

2. What was the reason(s) for first visiting your doctor for your cough?*

3. How many times have you seen your doctor regarding your cough?

(0, 1, 2, 3, 4, 5+ times)

4. When did you last see you doctor regarding your cough?

(1 week ago, 1 month, 1-2 months, 2-6 months, 6-12 months, 1-2 years, 2-5 years, 5+ years)

5. Does your cough stop you from doing the things you would like to do?

(Frequently, sometimes, never)

6. Do you feel fed-up or depressed because of your cough?

(Yes, sometimes, never)

7. Does your cough disturb or worry your partner, family or friends?

(Yes, sometimes, never)

8. Does your cough affect your quality of life?

(Severely, moderately, a little, not at all)

Question 9. Has a diagnosis for your cough been given?

(Yes/No)

10. If you received a diagnosis for your cough, what was it?

11. Do you feel your doctor/specialist has dealt with your cough thoroughly?

(Yes/no)

12. Have you ever attended a specialist Cough Clinic?

(Yes/no)

13. Would you consider attending a specialist Cough Clinic if available to you?

(Yes/no)

14. Do you currently smoke?

(Yes/no)

15. Have the treatment(s) for your cough worked?

(Yes, a little, no)

16. Please tell us what, if anything, has worked?*

17. Have you found over the counter pharmacy (non-prescription) cough suppressant medications effective?

(Yes, a little, no)

18. Would you like more information on chronic cough to be available?

(Yes/no)

19. If yes, what further information would you like?*

20. What other support do you think would be beneficial?*

21. Would you like to receive further information about the ELF/ERS chronic cough taskforce and patient involvement?

(Yes, no)

Demographics

Age

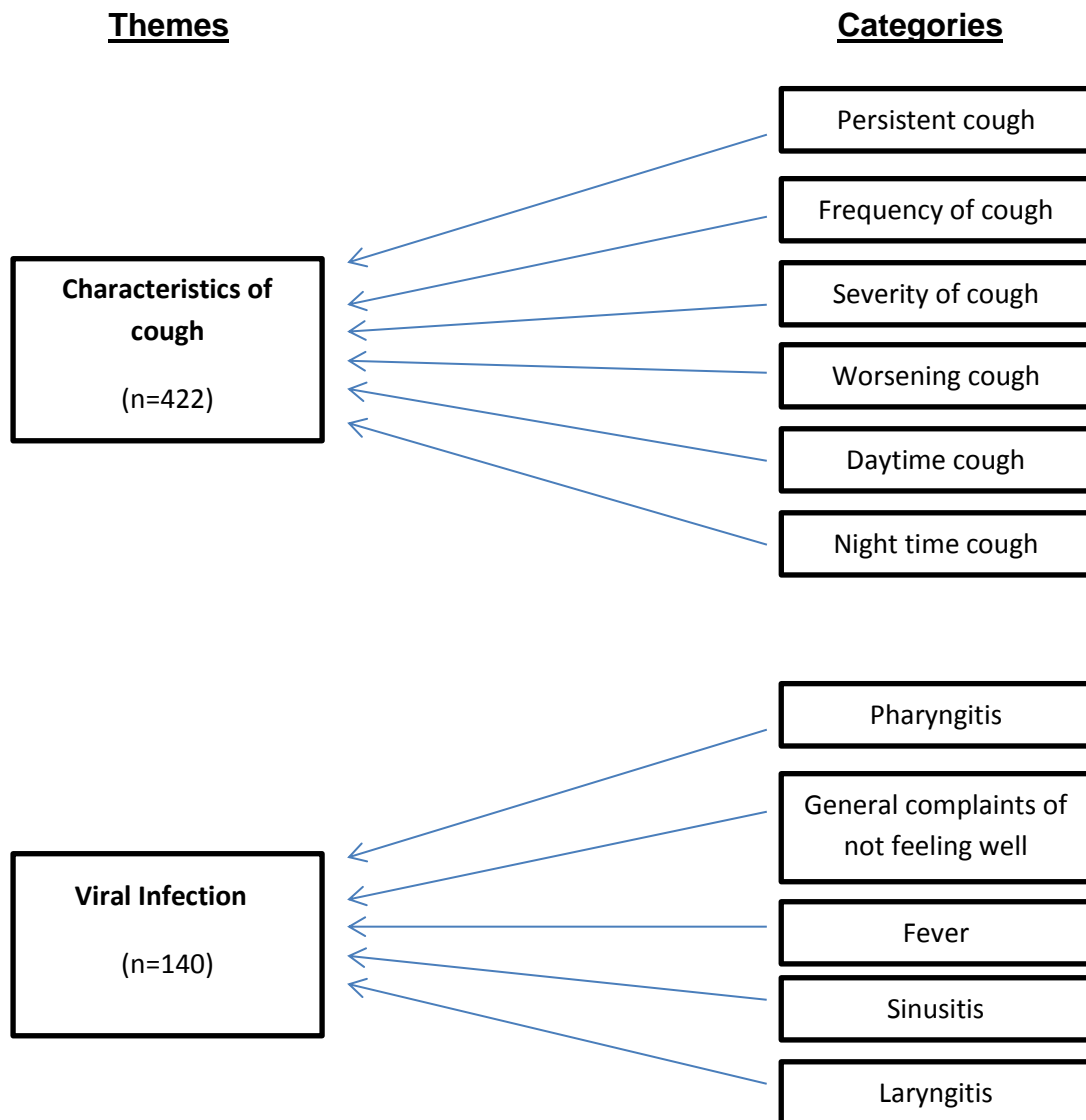
Country of Residence

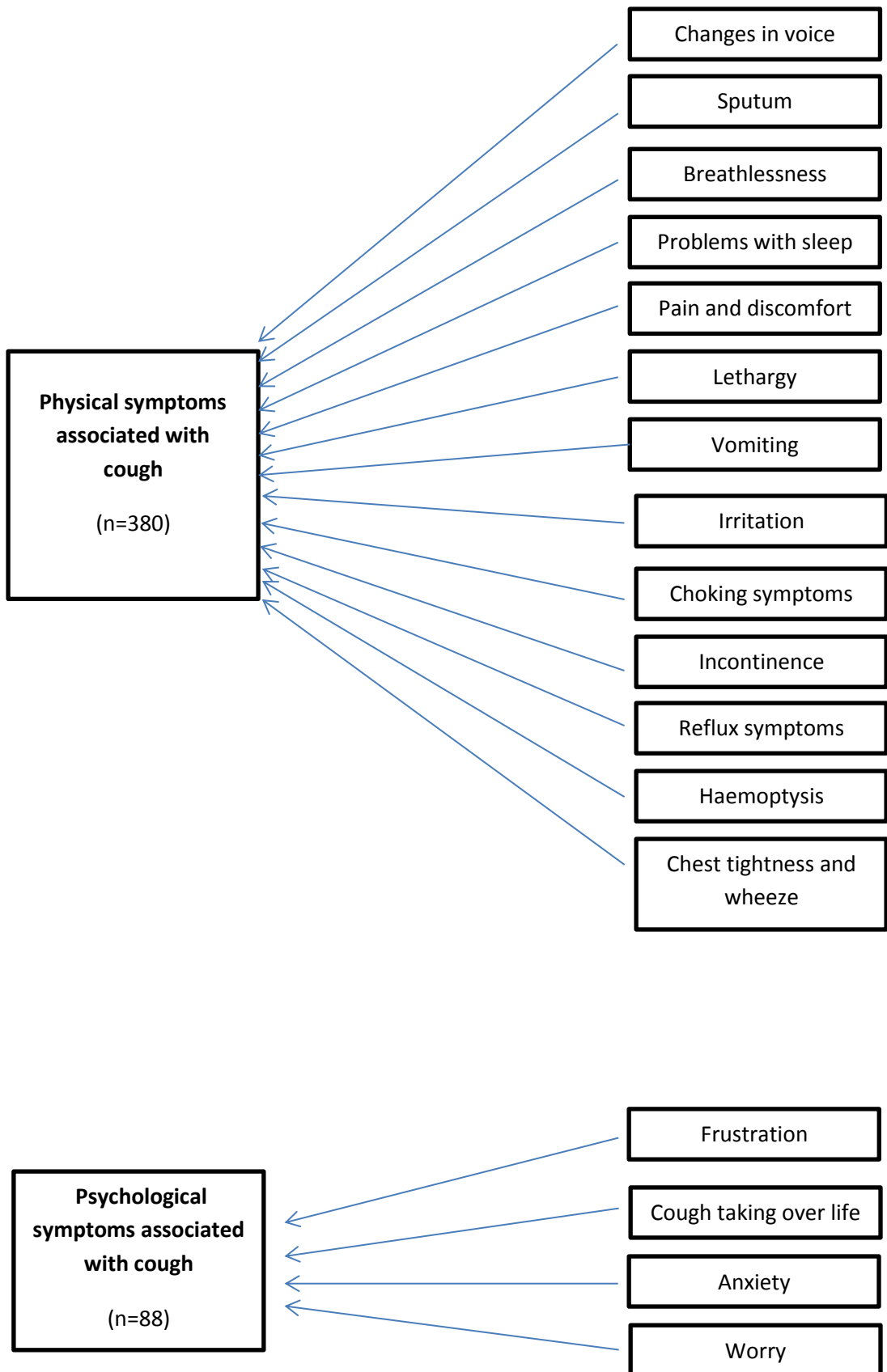
Gender

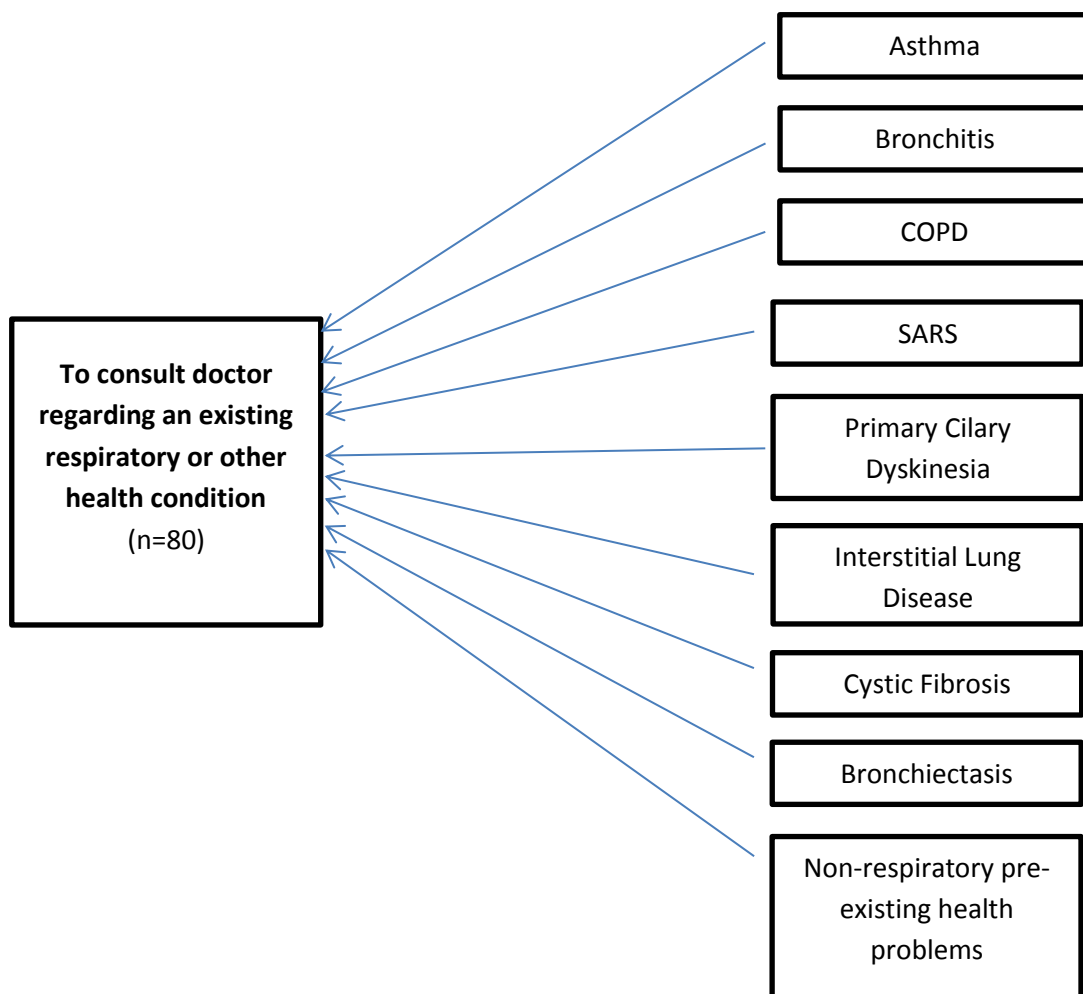
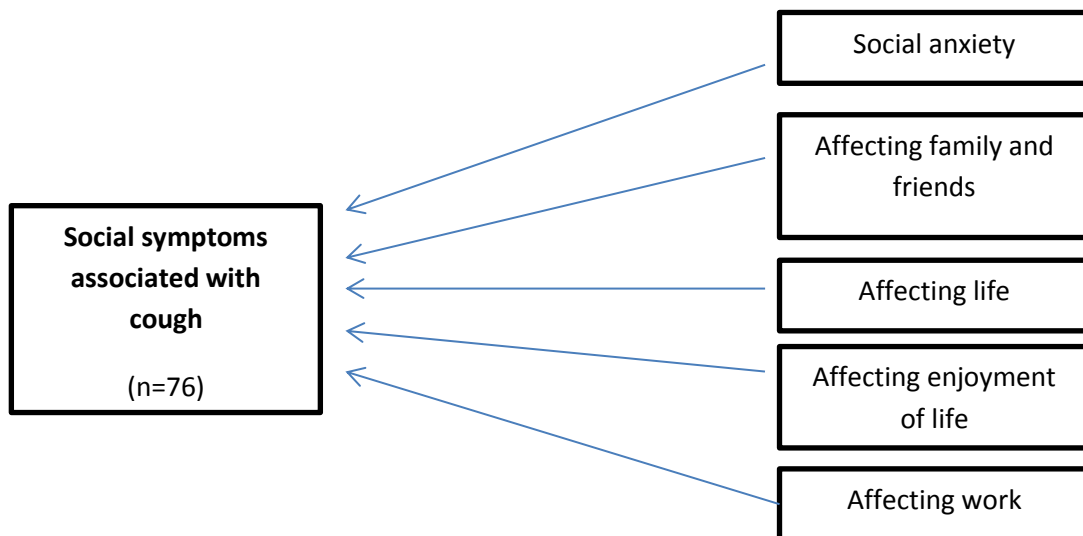
Ethnicity

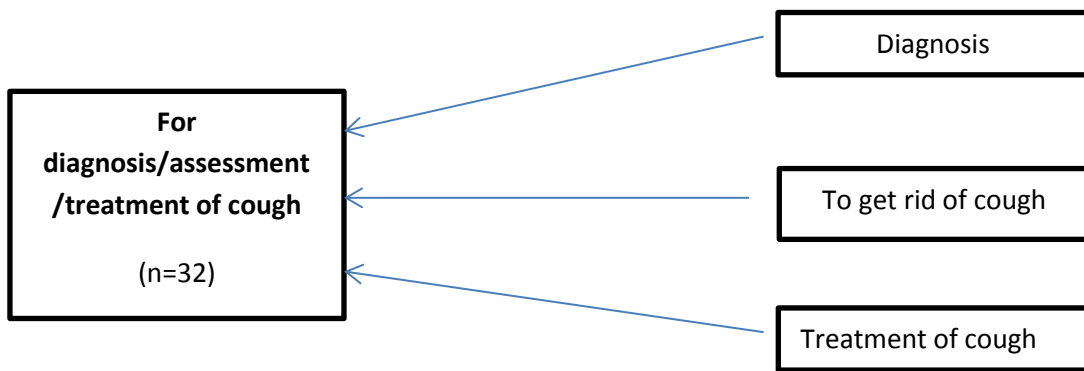
(White Caucasian, Black Caribbean, Black African, East Asian, South Asian, Mixed, Other)

Online Appendix B: Reasons for why respondents initially consulted their doctor about their cough









Online Appendix C: Quotations from participants: why they first consulted their doctor

Characteristics of the cough

“Because it was continuous” (Italian responder)

“An increase in the number of coughing fits each day: between 10 and 15” (day and night) (French responder)

Physical symptoms associated with cough

“I was coughing so much my chest hurt” (Spanish survey responder)

“Breathlessness and wheezing” (Polish survey responder)

“I couldn’t hold conversation without coughing” (English survey responder)

Viral infection symptoms

“Chest infection” (English survey participant)

Psychological symptoms associated with cough

“Because my cough was beginning to take over my life” (French survey responder)

“Because of the distress it was causing myself and other close persons” (English survey responder)

To consult a doctor about existing respiratory or other health condition

“Pulmonary fibrosis, COPD” (Polish survey responder)

“Have cystic fibrosis” (English survey responder)

Social symptoms associated with the cough

“The coughing interfered with my interactions with other people” (Lithuanian survey responder)

“My cough was degrading my quality of life” (Bulgarian Survey responder)

For diagnosis/assessment and treatment of the cough

“Clarify causes” (German responder)

“To try to get a cure” (German responder)

Online Appendix D

Information and support requested by participants (Themes and quotations)

Treatment

“How to treat it” (English responder)

“An effective cure” (Italian responder)

Causes

“Explanation of the cause” (German responder)

“Explain the causes of the cough because I am lost” (Polish responder)

Self-help and alternative therapies

“I don’t know, something we could do about it on our own” (Spanish responder)

“How to manage the coughing, things to avoid etc” (English responder)

“Herbal alternatives when medication simply does not work” (English responder)

General information in a variety of formats

“Provide information on-line, with daily updates if possible” (Spanish responder)

“All info that might help me get rid of this inconvenience” (Swedish responder)

“Links to internet sites so that I can obtain information on my problem” (Greek responder)

“Brochure for patients” (Russian Responder)

Better understanding, awareness and support from doctors

“To be taken seriously by the doctors” (German responder)

*“Information for Doctors on how to treat as they don’t seem to be very aware”
(English responder)*

Assessment

“What specific test to get done” (Italian responder)

“Differential diagnosis” (English responder)

Information on access to specialist cough clinics

“Details of specialist cough clinics” (Italian responder)

“Referrals to specialist to be made when symptoms have persisted for an extended period” (English responder)