

**Supplementary File 4**

**Themes Identified in the synthesis of 6 studies.**

Theme 1	"You've only got a cough"
Multi-Faceted	<p data-bbox="801 432 2134 544">"If it was you know cancer or something people would look for a cure whereas this is just "You've only got a cough" P11 [1]</p> <p data-bbox="801 587 2145 699">"It's retching, its struggling for breath, its vomiting, nose running, headaches just with the coughing" P5 [1]</p> <p data-bbox="801 742 2107 853">"Sometimes I throw up a lot of mucous and I really cough a lot at night...sometimes I wet on myself I cough so hard it makes my head hurt" User128 [2]</p> <p data-bbox="801 896 2134 936">"Coughing can cause a loss of concentration, momentary difficulty in breathing or pain in my lungs"[3]</p> <p data-bbox="801 979 2123 1091">"You're just coughing and coughing and coughing and you get all heated up, lightheaded, feel like you want to pass out because the severity of the cough has taken so much out of you"(Patient 13). [4]</p> <p data-bbox="801 1134 2123 1246">"I have severe pains, like in my chest and in my back, in my abdomen. I had a muscle or something popped out just on my chest, like the size of the bb finger overnight from the coughing. I'm just really</p>



	<p>You're just coughing so hard that you have to try to catch your breath [5]</p> <p>"At times it'll get bad enough, where I blackout, or I feel like I'm going to blackout, like I can't get my breath, I'm choking constantly" (Patient 4) [4]</p> <p>It can get so severe that I literally have to go to the sink just to hold on just to keep my body.(Patient 9)[4]</p> <p>"Afterwards, I sometimes get dizziness like severe dizziness"(Patient 1, male, age 44 years). [4]</p> <p>"I'm coughing my brains out, let's put it that way. My head is spinning after"(Patient 12, female, age 75 years) [4]</p> <p>"I find it very agonising—that's the word I was looking for, agonising. It just seems to be like every part of your chest and all around there ache, like really ache, when it's really bad"(Patient 5, female, age 70 years) [4]</p>
Idiosyncrasies	<p>It's like somebody has went in with a razor blade and just slashed it, it's so painful, but then when you've had a drink ... start to get really itchy but so does my throat and I really want to swallow something sharp just to scratch it. (P1) [1]</p> <p>'It's like electric pylons ... buzzing going on in my head and ... it's all mixed up blurry picture ... I couldn't walk on' (P3) [1]</p> <p>"I find myself, like doubling over either trying to get the air in or the air out" [5]</p> <p>"It's almost like someone is squeezing your neck from both sides, like a hard pressure and pain" Patient 15 [4]</p>

	<p>“And I sometimes get some numbness in my extremities like if I’m having a really bad episode I’ll feel numbness in my hands and my feet”(Patient 1, male, age 44 years).[4]</p>
<p>Triggers</p>	<p>“Coming into a clinic room like this with new smells and things was enough to trigger it and I would wanna cough.” [5]</p> <p>“I can’t stand the smell of perfume. I’ll start coughing.” [5]</p> <p>“Activity. Anything. Getting out of bed, walking to the bathroom, walking to the family, to the kitchen, to washing the dishes. Any of that. Walking from my car to the parking lot. Any sort of activity.” [5]</p> <p>“Exercise was the main thing that made me cough.” [5]</p> <p>“For me personally [my cough frequency] during the day is worse because that’s when I’ll have more triggers. If I use my voice too much that can be a trigger. Could even be a certain way the wind blows on my face or by my ear that will trigger a sort of spasm or episode” (Patient 1). [4]</p> <p>“It definitely gets worse when I’m having, like, seasonal allergies or anything that would, like, make me have more postnasal drip.” [5]</p> <p>“I think it might have something to do with—I do have allergies.” [5]</p> <p>“Laundry usually requires vertical motion of the body. Lifting clothing to dry them. It was so hard that I had to ask somebody else to do it” [3]</p> <p>Dryness “Certainly, if it feels drier, I feel like that makes it a little bit worse.” [5]</p>

<p>No rhyme nor reason</p>	<p>“There’s no rhyme or reason to it you know, there are certain things that aggravate it but...it can just happen so we are never quite sure so you’ve always got that thought that something could happen” P5 [1]</p> <p>“Generally speaking, when cough happens, it comes out of the blue. It’s unexpected” [5]</p> <p>“I haven’t found anything specific that makes me cough.” [5]</p>
<p>Daytime Cough</p>	<p>“I’d say worse in the morning.” [5]</p> <p>...but normally during the day I’ll have just attacks of four ,five, or six coughs and then it will clear up. [6]</p> <p>“Yeah I agree mine’s all day long, sometimes it’s just little coughs sometimes it’s big ones...”(Patient 4, female, age 62years).[4]</p> <p>“So for me I don’t think I cough much at night at all. But crazy during the day” (Patient 9, female, age 50 years). [4]</p> <p>“During the day there’s more frequency” (Patient 12). [4]</p> <p>“[My cough] is very rare at night, mostly during the day—actually always during the day” (Patient 6) [4]</p> <p>A dry cough. It troubles me almost every day [3]</p> <p>“For me it would be intermittent coughing during the day” [6]</p> <p>“I’ll have a severe cough at least once a day, sometimes two and three times a day with my short coughs, the easy coughs happen, some days 10 times some days maybe 50 times” Patient 15 [4]</p>

<p>Night time cough</p>	<p>... 20minutes sleep and then you'd be awake coughing again ... it's not worth it, I may as well get up. [1]</p> <p>Sometimes I can't sleep at all night. I have to get up and go get in a chair, because whatever is coming out of my head or my throat is sitting in this bronchial tube down there, and it's messing up everything. And it's continuous.[6]</p> <p>...I cough a lot when I go to bed. I lay down, and I find that makes me cough a lot [6]</p> <p>I'll cough. Sometimes I can't sleep at all night [6]</p> <p>For me it's not being able to sleep, you know, just waking up coughing, coughing, and coughing [6]</p> <p>"Yes, I find at night, like most nights, my nights are just as bad as my days, just out of the blue I'll start coughing. Doesn't matter if I'm on my back, my side, sometimes I have to sit up and just cough it out, or I leave the room and go sit somewhere just because I can't catch my breath" Patient 10 [4]</p> <p>Now it is a constant cough, is intensified at night (all the night), I can't sleep. Therefore, I am very tired, with anxiety, irritable, desperate" User #097 [2]</p> <p>"Sometimes I never get any sleep. I just cough, cough, cough." [5]</p> <p>"It interrupts sleep." [5]</p>
<p>Constant cough</p>	<p>"It's just constant. It seems like its constant irritation." [5]</p> <p>"Just coughing all the time. Cough after cough after cough." [5]</p> <p>"I don't keep track of how many times I cough a day, I just know I cough constantly" (Patient 10). [4]</p>

	<p>Uncontrollable cough “It just doesn’t seem like anything stops it.” [5]</p> <p>“I felt, like, out of control. And it would—it just never stopped.” [5]</p> <p>Mine's just all the time. I cough all the time.[6]</p> <p>Umm, I pretty much cough all day and all night, but I've taken some medication. [6]</p> <p>Now it is a constant cough, is intensified at night (allthe night), I can't sleep. Therefore I am very tired,with anxiety, irritable, desperate.[User #097] [2]</p>
Exhaustion	<p>“I think it just wears you out “cause it just using all of this energy trying to hold back a cough.... And you just get exhausted from the whole thing” [5]</p> <p>“When I finish it one of my bad sessions, I feel extremely exhausted” [4]</p> <p>“...one of those that goes on and on and on and I think “I can’t do with that, it’s tired me out” ...you know drained” P2 [1]</p> <p>“You just feel very weak, like you just feel sick and helpless. It takes a lot out of you, a lot of energy”(Patient 15). [4]</p>
Cough as an identity	<p>“I would say in my case that it’s less about violent frequencies and more of a constant throughout the day. I must cough at least 200 plus times a day. And I don’t seem to go through a period of not coughing. It’s become just a part [of me]” (Patient 3). [4]</p> <p>“They don’t even know me by name, but they know me by my cough” P14 [1]</p> <p>“It’s becoming part of life at the moment, it’s just becoming...that’s just me, it’s like having blue eyes, that just I’ve got a cough” P1 [1]</p>

	And when you meet people it seems to define you, 'How's your cough?' you know. It's very much people remember, 'Aah you're the one that coughs'. (P5) [1]
No two days the same	Some days are...much worse than others. [6]  No, I think every day, you know, every day is different [6]  ...Some days I don't have anything like that, and all of a sudden I might have one [episode] [6]

<b>Theme 2</b>	<b>"Constant cough and constant worry"</b>
Social Isolation	<p>"It's definitely affected my social life. I literally did virtually nothing all summer but cough, feel bad, and sleep." [5]</p> <p>"The whole thing about missing out on, you know, on things that you wanted to do, and, and it's, uh, you don't wanna be disrupting people or making them worried that you're coming along with this contagious disease." [5]</p> <p>'And a sadness because it's, I should be able to go, you know ...' (P5) [1]</p> <p>'The cough controlled me, I had no control at all over when I coughed, how often I coughed, how strong the cough was ... it got to the point where ... I didn't even want to go out to get my shopping' (P12) [1]</p> <p>I stopped going to church because people look at me like I have something really bad. Sometimes I throw up a lot of mucous and I really cough a lot at night...Sometimes I wet on myself I cough so hard and it makes my head hurt. [2]</p> <p>I can't go anywhere without fear of having these attacks...I've become withdrawn from society. [2]</p> <p>I can't go anywhere without fear of having these attacks [2]</p>



	<p>“I have to stop singing, and I’m like, oh, ‘cause I know that I’ll cough. And I’ll have to stop...” [1]</p> <p>“Well, there’s things like going to a play or, um, book club discussions...where you’re gonna be talking a lot ‘cause that’s a trigger for me.” [1]</p> <p>And that then trickles down here, and then I cough like the devil... I get-it sticks here, great big chunks of it will stick here-can't get it out. And I cough, and cough, and cough, and then if you go to a restaurant and start coughing, they throw you out. [6]</p> <p>“It’s annoying, and I am always worried about going out, and about and what I would do if I couldn’t stop coughing again when I am on a train or a plane” [3]</p>
Mitigation strategies	<p>I can’t do any more than that ... I refuse not to go out, I refuse to stop socialising. I can’t let it rule because I would end up with nothing. (P14) [1]</p> <p>I can’t go anywhere without a handkerchief or a bottle of water, everywhere I go ... It’s not your lipstick and your keys anymore. (P5) [1]</p> <p>‘But I do still go [work dinners] from time to time but [Name of husband] just basically does all the talking’ (P12) [1]</p>
Unwanted Attention	<p>“You need to get that cough checked out because you always do it.” [5]</p> <p>People often ask, ‘Are you okay?’ but obviously I’m not all right at all [3]</p> <p>‘Not that you want anybody’s sympathy but you know you think “god have I got to explain myself and you’re not even interested”’ (P8) [1]</p>

	<p>“Some folk they can look at you, some folk are not very nice...if the place is really, was really crowded and things it was an embarrassment quite frankly...I felt like two fingers up at them” P9 [1]</p> <p>“They’ve obviously really noticed it...to come up to a total stranger...I think it just makes you really aware of how loud it is and how noticeable it is to other people” P11 [1]</p>
Stigma	<p>Obviously they don’t know I have a problem with a cough so they must just think I’m a big walking germ. (P14) [1]</p> <p>‘people see me in a bad light when they just see the cough’ (P9) [1]</p> <p>‘embarrassment of having to explain that I haven’t got you know like the plague’ (P14) [1]</p> <p>It’s embarrassing sometimes, too. I mean, either you're-if I'm standing in a grocery line and start coughing, people are looking at me like I'm contagious with something [6]</p> <p>“I just feel like it’s affected me mentally. I feel very self-conscious about it.” [5]</p> <p>“It’s a problem when there are people around me such as when I am on a train. People would think I have COVID-19 nowadays, or a cold during the pre-COVID era. In such cases, I would endure it or hold my mouth tightly and try to keep the sound as low as possible” [3]</p> <p>And that then trickles down here, and then I cough like the devil... I get-it sticks here, great big chunks of it will stick here-can't get it out. And I cough, and cough, and cough, and then if you go to a restaurant and start coughing, they throw you out. [6]</p>

Justification to others	<p>“Not that you want anybody’s sympathy, but you know you think “god have I got to explain myself and you’re not even interested” P8 [1]</p> <p>“...You should just stop coughing. Just stop. Don’t do it. And I say but I get this tickle and I have to cough, you know, and it’s all day” [6]</p>
Lack of freedom	<p>Driving is scary. If I cough when I’m holding the wheel, I can’t see ahead. I don’t drive much now [3]</p> <p>It’s a problem when there are people around me such as when I am on the train. People would think I have COVID-19 nowadays, or a cold during the pre-COVID era. In such cases, I would endure it or hold my mouth tightly and try to keep the sound as low as possible [3]</p> <p>I started to wheeze just by going up the stairs at the station. It’s hard to walk in the station because I feel like I’m walking fast to keep up with the crowd. Going up and down the stairs is a big burden for me [3]</p> <p>Sometimes I can’t go shopping or cook if it’s too bad [3]</p> <p>To me that strikes me as always a very serious bout of coughing, because obviously, oxygen wasn't getting where it was supposed to be getting. Um, and I find this is freaky, especially if you're driving, you know, and your coughing, and all of a sudden you're dizzy [6]</p>
Career impact	<p>“I noticed my voice was becoming more hoarse near the end of the day, which made it difficult to do my job.” [5]</p> <p>“It’s embarrassing when I’m trying to work or, you know, I’m in a group and all I can do is hack.” [5]</p> <p>I was talking to the person that was reporting to me and giving her direction or what to do, that I could not complete the sentence without coughing. And that was so annoying and embarrassing. [6]</p> <p>I had one on a job interview, and by the time I was done trying to speak, I sounded like Minnie Mouse on speed. I was so squeaky. But it [the cough] wouldn't stop, just would not stop [6]</p>

	<p>The final cough was absolutely – absolutely retched and, ugh, I think was XXXXX who mentioned embarrassed. Ugh, I had a lot of – I had a number of meetings that I –that I had to go to and, uh, I couldn't stop coughing in those things. [6]</p> <p>Coughing often interrupts my work [3]</p> <p>It becomes a nuisance to work. I feel like I don't want to work anymore [3]</p> <p>Regarding cars, cough doesn't generally restrict me on the job, but it does prevent me from working outside of the office. This stopped me from pursuing my career plan [3]</p> <p>I have left early several times, but I never take an entire day of. I have to leave early because I have a bad cough, or I have to go to the hospital... only by about 30 min to an hour [3]</p> <p>I'm taking a leave of absence on company orders. When it began, I was suffering from the same difficulty in breathing, my daily activities were limited, and I had trouble conversing [3]</p> <p>I had a coughing jag at work one day that was totally embarrassing. I couldn't stop. ...occasionally I'll have a real episode, but it's more just every once in a while [6]</p>
Impact on significant others	<p>It must embarrass him but he never lets on ... he just turns me in and cuddles me in ... as if you know, protecting me from the world ... (P5) [1]</p> <p>I don't want anybody fussing you know that I say 'No, no I will be alright in a minute' ... I just try and make light of it so they're not concerned ... (P2) [1]</p>

	<p>I don't really know how often I cough, 'cause I'm oblivious to it many times. My wife will tell me that I'm on the telephone coughing. So, that's part of probably just being not as aware sometimes as other people would be.[6]</p> <p>Both my parents and wife know about it (my cough), so it doesn't affect us much [3]</p> <p>"My husband was sitting staring at me waiting for me to—I felt like he was waiting for me to die, and it was like, 'is she ever going to get her breath back?', and I finally got it calmed down enough to get my breath back and then I'm sitting and I'm deep breathing"(Patient 4). [4]</p> <p>I don't really know how often I cough, 'cause I'm oblivious to it many times. My wife will tell me that I'm on the tele-phone coughing. So, that's part of probably just being not as aware sometimes as other people would be.[6]</p>
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Theme 3	"No light at the end of the tunnel"
Frustration	<p>"My normal doctor here, my regular doctor... He's been just so frustrated because he can't find the right answer." [5]</p> <p>'I know he [doctor] exhausted every avenue and I've still got this cough' (P10) [1]</p>
Lack of solutions	"They never offered a solution. It was just more of the same." [5]
Protocol driven Care	<p>"I think she's done her job as far as following the protocol that she's been given." [5]</p> <p>"I felt that she took me seriously...I just felt like there was this protocol, and, uh, yeah. It just took longer." [5]</p>
The diagnosis	<p>"I feel like I can finally stop searching for what's wrong with me." [5]</p> <p>"Just getting diagnosed is, like, the burden has lifted. Everything is better." [5]</p>

	<p>"I think it was actually, it was a big relief because I could, like, finally pinpoint what was wrong with it." [5]</p>
Unpractical therapy	<p>"I mean if I could control the cough, it would be great. I've been using—I've been seeing a speech therapist to try to help me control the cough and she's heard me cough a couple of times and she'll say to me, 'Oh, you can control that just swallow it down', [and] it's like no I can't swallow it down, because then I'll start to choke so it's a no-win situation for me" (Patient) [4]</p> <p>"It'd be nicer to know if there was something easier to get rid of it 'cause therapy, you know, is always a longer process." [5]</p> <p>They sound practical but they're not practical ... a cup of steam which is fine if you're sitting but then you don't sit all day ... (P14) [1]</p>
Lack of efficacy	<p>If I catch it right, it's good. If I don't catch it right it's not so bad. (P9: water suppression) [1]</p> <p>Now I've got a 50/50 chance of it being a good day or a bad day. (P5: morphine) [1]</p> <p>If you break your leg and you get it fixed, it's fixed so I thought having this operation which he said initially it would get rid of this cough, right that's another thing fixed ... (P8) [1]</p> <p>I have it under control with the medication, but I still get some fits that usually last five minutes, and they're rather intense, uh, in coughing.... [6]</p> <p>"At the beginning, I know I could take cough drop, and it would make it less severe or I could drink water and it my control a bit, but I mean those possibilities are long gone way in the past, nothing controls it"(Patient 14). [4]</p>
Pharmaceutical Therapy	<p>"I don't want to take any medicine if possible. Medicines are not natural, so I feel like they are not good for me" [3]</p> <p>"The medicine is expensive. I take a lot of it. It has become an economic burden" [3]</p>

Desperation	<p>You are willing to sort of grasp at anything ... if they told me to hold my head underwater for ten minutes a day I would try and do that you know. (P7) [1]</p> <p>I would like to try (new medication). If I was asked to be a human guinea pig for a clinical I would. [3]</p>
Self-Blame	<p>“There is a real component to my cough, but there is a learned component.”[5]</p> <p>“That it is a vicious cycle with the cough and clear that, um, every time I do that I just irritate my, um, throat and vocal cords...” [5]</p> <p>“And I then to get into that stage, I am the one who is initiating the severe cough, I’m trying to cough up phlegm and nothing is coming up, although I can feel it there. [...] So I am the one who instigates that severe cough as opposed to it just happening on its own” (Patient 6) [4]</p> <p>You can easily feel guilty with the [healthcare] system ... go through all the routines ... ‘none of this is any good’ so you begin to think ‘Oh God, it’s me’ ... I should be better; I should be able to control it. (P7) [1]</p> <p>Well is it me or is it ... is there something in the atmosphere that is doing it? ... It’s like the 50million dollar question. (P14) [1]</p>
The never ending cough	<p>“I don’t think I’ve got the ability anymore to stop my cough” (Patient 12) [4]</p> <p>“I cough more than I say I do because I said it, it’s part of your life, whether you like it or not, you can’t control it, or I can’t control it, it just comes” (Patient 7) [4]</p> <p>“All you can do [is] cough...you can’t control it [during an episode]” (Patient 1) [4]</p> <p>“I don’t have an ability to control it once it starts coughing that’s it until it stops...and yeah so there’s no ability to control it, and it does get more severe as I’m coughing”(Patient 9). [4]</p> <p>‘Not being able to say a light at the end of the tunnel where it’s going to be “Oh it’s okay, it’s only going to last another couple of month because I am going to have this done,” I can’t see it ever getting any better’ (P1) [1]</p>

	It's never changed in those 18years ... unless a miracle occurs I will have this cough 'til I die. (P6) [1]
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### **References**

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