

Development of a Conceptual Model of the Patient Experience in Small Cell Lung Cancer: A Qualitative Interview Study

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Supplementary materials

S1 Table 1 Concepts related to disease-related symptoms and impacts in SCLC

Domain	Subdomain	Concept	Exemplary quote
Organ-specific symptoms	Cough	Cough	<i>"[It's] an annoying, dry cough, kind of scratchy, a tickly kind of feeling from inside... it doesn't stop for a while and then it all just seems to subside on its own." (US010)</i>
		Coughing up blood	<i>"When it first started happening, I didn't notice that it was coming up bloody. And then all of a sudden, I did. That was a little scary because that's not so normal." (US005)</i>
		Coughing up phlegm	<i>"Well, it was yellow for a while, and then it started getting specks of blood in it, and I was a little concerned, but I figured I'd been coughing quite a bit. And then it would get darker streaks in it, and now it's back to spotty. So it's not as dark and streaky, but it's still there." (US006)</i>
		Hoarseness	<i>"Like I have a hoarser-type voice, instead of it being super clear. I just feel like the coughing has aggravated my esophagus, and it's just I'm always sounding a bit like I'm congested or something." (US002)</i>
	Chest or arm/shoulder pain	Chest pain	<i>"Like something tightening in my chest, like pressing on my chest. It feels like something heavy is on my chest." (US003)</i>
		Arm/shoulder pain	<i>"I did have pain in my abdomen, upper abdomen, soreness in my shoulder initially... it wasn't alleviated by changing positions." (USA4)</i>
	Difficulty breathing	Difficulty breathing	<i>"[Difficulty breathing] is like if you're having an asthma attack." (US003)</i>
		Difficulty breathing at rest	<i>"[Difficulty breathing was there] whether I was doing things or not." (US004)</i>
		Difficulty breathing upon exertion	<i>"If I got up and went into the kitchen and got a drink of water, that would bring on the breathlessness or if I walked up our half a flight of stairs to my bedroom, that would bring on gasping for air." (USA4)</i>

		Wheezing	<i>"It was more of a sound that came out of my mouth or my throat, just a little wheezing. But that was it. It wasn't coughing or breath or pain." (SD-04)</i>
Systemic symptoms	Pain	Pain	<i>"I was thinking that I was having – I don't know, really, what a heart attack feels like, but it just felt really heavy and painful – painful in my shoulders. There was a lot of pain." (US006)</i>
	Fatigue	Tiredness	<i>"So tired. Like, you know when you get up in the morning and you have your coffee, you feel like you have a little bit more energy or enough oomph to get active or to be physical? Even after having my coffee, I just feel like I'm just kind of tired, like lack of energy, it feels like, even though I know I slept enough hours in the night, maybe I didn't get enough sleep. That's what it feels like. Just tired." (US009)</i>
		Feeling weak	<i>"Well, my whole body is tired. It's like I need to sleep forever. I'm very weak." (US006)</i>
		Need to sit or lie down	<i>I feel like I can't even stay vertical. I have to lay down." (USA5) (US010)</i>
		Lack of energy	<i>"I think it's basically that my energy level has been cut down." (US004)</i>
		Thinking clearly/concentration problems due to mental tiredness	<i>"It's like I'm not quite thinking that clearly and I can't concentrate. And I just – I know I really have to have a nap." (USA2)</i>
	N/A	Appetite loss	<i>"I ate more hearty, I guess you could say before, but I pretty much don't go back for seconds these days." US010</i>
	N/A	Dizziness	<i>"My equilibrium, my balance would start to go because of the lightheadedness. And so, things like stairs or carrying any kind of a heavy load became very difficult if not impossible." (SD-02)</i>
Physical functioning	Daily activities	Symptoms limiting daily activities	<i>"I can't clean my house, even, like I used to. I have to have a friend come over and help me. It's the smallest little tasks that I can't even think about doing, because I'll just get too worn down." (US006)</i>
		Reduced endurance	<i>"[SCLC has changed] my endurance in doing things." (USA4)</i>

	Underlying factors limiting daily activities	Reduced strength	<i>"I don't use the muscles like I used to use them... I used to lift the weights and do different little exercises. I don't do that. I'm very, very weak." (US014)</i>
		Reduced balance	<i>"My equilibrium, my balance would start to go because of the lightheadedness. And so things like stairs or carrying any kind of a heavy load became very difficult if not impossible." (SD-02)</i>
	Impacts on movement	Reduced bending over	<i>"I basically couldn't look down or – and definitely not bend down. I would get very, very dizzy and faint. So that was really hard. So that meant that I couldn't be independent. I had to have people actually get whatever I needed from the floor or lower cabinet or something like that." (USA2)</i>
		Reduced squatting	<i>"Squatting is picking up stuff and standing up. I think I could pick something up. But I try not to pick up any really heavy—[because of that] throwing me off balance—or something too large and awkward." (US008)</i>
		Reduced walking	<i>"If I talk and walk, I'll get short of breath. Always carrying something, like bringing my groceries from the car, I'll be short of breath, even though it just doesn't seem like very much, but I'll get short of breath." (USA2)</i>
	Role functioning	Stopping or limiting work or hobbies	<i>"It's really probably a very personal issue because I'm an academic, so because of this – I mean, I used to present and teach, and now I have to consider other things, because I know people don't want to hear me for a long time. Even when I'm in meetings, some people don't really want me to present. Everybody thinks I have pain when I'm talking, which I don't, but I do lose my voice after a certain time period. So, it's really impacted me professionally." (USA5)</i>
Difficulty sleeping	N/A	Difficulty sleeping	<i>"Yeah, there have been effects on my sleep. It's broken up. It's not eight hours solid." (USA3)</i>
Weight loss	N/A	Weight loss	<i>"I don't have a lot of weight to lose and I've lost weight and I look really frail." (US001)</i>