

Supplementary Material

Symptoms and Experiences With Small Cell Lung Cancer: A Mixed Methods Study of Patients and Caregivers

D Gwyn Bebb^{a,b}, Cressida Murray^c, Andromachi Giannopoulou^d, Enriqueta Felip^e

^aAmgen, Thousand Oaks, CA, USA

^bUniversity of Calgary, Calgary, AB, Canada

^cHumanBranding Inc., Toronto, ON, Canada*

^dAmgen (Europe) GmbH, Rotkreuz, Switzerland*

^eVall d'Hebron University Hospital and Vall d'Hebron Institute of Oncology,
Barcelona, Spain

*Affiliation during the conduct of the study

Corresponding author:

D Gwyn Bebb, BMBCh, PhD, FRCPC

e-mail: dbebb01@amgen.com

Supplementary resource 1 Video diary questions/activities.

ASSIGNMENT 1 – DAY 1: About Me

- Nice to meet you! How are you feeling today? When it comes to how you are feeling both physically and emotionally, is today a particularly GOOD DAY, a particularly BAD DAY, or just a normal day? [Choose in Poll]
 - Please tell us why you made this selection in a minute-long recording – why is today good, bad, or normal?
- Now we'd like you to complete a video exercise. Please use your camera to introduce yourself and your world – where do you live, what you like to do, what's important for us to know about you?
- Now we'd like to understand what changes may have occurred in your life since your lung cancer diagnosis that are visible in your home. Please post a video showing us what might be different in your home since your diagnosis.

ASSIGNMENT 2: "My Symptoms" journal assignment

- Send ASAP after Assignment 1.
- We would like to introduce you to a special journal-style assignment called "My Symptoms" that you'll use to document any physical symptoms you experience during the project.
- When you experience any physical symptoms related to lung cancer or your lung cancer treatment, tap on the "My Symptoms" assignment and share the symptom in a 30-second audio recording where you can describe whatever you are feeling.
- You can document any symptoms related to your disease, any symptoms that may be a side effect of a treatment, any physical limitations you're experiencing, or any time you are feeling better than you were beforehand.
- You can document an audio recording at any point throughout the 5-day journal.

ASSIGNMENT 3 – DAY 2: My Treatment

- How are you feeling today? When it comes to how you are feeling both physically and emotionally, is today a particularly GOOD DAY, a particularly BAD DAY, or just a normal day? [Choose in Poll]
 - Please tell us why you made this selection in a minute-long recording – why is today good, bad, or normal?
- Today we want to talk about treatment.
 - Please post a photo of something that reminds you of your treatment.
 - Please tell us why this reminds you of your treatment [text or audio].
- What do you hope will come out of being on this treatment? Do you have any goals or things you would like to do? Show us in a 60-second video.

ASSIGNMENT 4 – DAY 3: Physical Impacts

- How are you feeling today? When it comes to how you are feeling both physically and emotionally, is today a particularly GOOD DAY, a particularly BAD DAY, or just a normal day? [Choose in Poll]
 - Please tell us why you made this selection in a minute-long recording – why is today good, bad, or normal?
- Please make a 90-second audio recording describing the symptoms or physical impacts you typically experience due to your lung cancer. Have they changed over time? Have they changed depending on the treatment you were on?
- Show us in a series of pictures (2–3) the things you see as physical limitations for you now that you have lung cancer. Are there things you used to be able to do that you now can't, or have trouble doing?

ASSIGNMENT 5 – DAY 4: Social Impacts

Activities to explore the impact SCLC has had on the patient's relationships.

- How are you feeling today? When it comes to how you are feeling both physically and emotionally, is today a particularly GOOD DAY, a particularly BAD DAY, or just a normal day? [Choose in Poll]
 - Please tell us why you made this selection in a minute-long recording – why is today good, bad, or normal?
- Please gather some items in your home that remind you of the important relationships in your life. For example, what reminds you of a spouse/partner? Best friend? Children? Siblings? Grandchildren? The items you collect should be symbolic of the person or relationship, rather than be the person themselves or a photo of them.
 - First, please make a 90-second video explaining why these items remind you of the person or relationship. Why did you select these items to represent this person or relationship?
 - Now, with the same items, please tell us in a 90-second video in what ways these relationships have changed (if at all) since your diagnosis and treatment for lung cancer.
 - Lastly, please tell us in a 60-second audio recording about one thing that is really important to you in your relationships and social life.

ASSIGNMENT 6 – DAY 5: Emotional Impacts

- How are you feeling today? When it comes to how you are feeling both physically and emotionally, is today a particularly GOOD DAY, a particularly BAD DAY, or just a normal day? [Choose in Poll]
 - Please tell us why you made this selection in a minute-long recording – why is today good, bad, or normal?
- Please record a 60-second audio telling us about the emotions you find yourself experiencing frequently since your diagnosis with small cell lung cancer. How would you describe your view on life since your diagnosis?

- What worries or fears do you have when it comes to lung cancer? Please find something in your surroundings that represent those worries or fears in a 60-second video.
- What makes you feel hopeful? In a 60-second video please show us something that for you is hopeful or positive.

ASSIGNMENT 7 – DAY 1 TO DAY 5: My Symptoms

This section is the open journal that will allow you to add any thoughts or experiences that you would like to share with us relating to your physical symptoms.

- Each entry will be a 30-second audio recording where you can describe whatever you are feeling. Feel free to upload as many recordings as you'd like, at any point.

Supplementary resource 2 Caregiver community board questions/activities.

Day 1: About You/About the Patient and Their Diagnosis with SCLC

Activity 1: Getting to know you

1. To start, we'd like to learn a little bit about you. In as much detail as you are comfortable, please write a paragraph introducing yourself and answering the following:

- Where do you live?
- How old are you?
- Who lives in your household with you? Are you married? Do you have kids?
- What do you spend most of your time doing? Do you work, go to school?
- What do you do for fun?
- Anything else you think is important to know about you!

2. Life Mottos: From the 12 statements [show selection of 12 "life mottos"], please pick one you feel best represents your approach to life in general. Or, if you don't feel any of these statements represent how you feel about life in general, feel free to write down your own in the space below. Please explain your choice.

Activity 2: Understanding the caregiver role

3. In as much detail as you are comfortable, please tell us about your loved one and a few details about their journey with SCLC and how you came to be a caregiver for them. Please share details like how your loved one is known to you (i.e. parent, sibling, spouse, friend), how long ago they were diagnosed, what stage they are in in their condition, and at what point you became involved in their care.

4. Please review the following activities of daily living and on a scale of 1 to 10 (10 being high), share with us the impact lung cancer has on your loved one's ability to perform these tasks. Please explain your ratings.

- Mobility

- Bathing
- Sleeping
- Cooking
- Cleaning
- Transportation
- Working

5. Roles you Play: Still thinking about your role in looking after your loved one, review the images [show set of 12 images depicting different professions], which represent different roles or jobs that you might associate with certain characteristics or behaviors (e.g. police officers enforce things, teachers educate people). Please pick the image that you feel best represents you in your role as a caregiver. Please explain your decision.

- Have you always felt this was your role? Has it changed over time? Why or why not?
- In an ideal world, which role would you want to play? Please explain.
- Do you feel you are able to put in the right level of involvement? Why or why not?

Activity 3: Describe your day

6. Emotional Imagery: [show set of 18 images depicting different emotions] This is the last question today, but every day when you come to the board we will ask you this question first. Our goal is to understand how you and the person you care for are doing from day to day.

Looking at the images provided, please tell us which image best describes how you are doing today and which one best describes how the person you care for is doing? Use the text box to tell us why you picked this image and what is happening today with regards to the physical, social, and emotional impacts of lung cancer on you and your loved one.

Day 2: SCLC/Treatments

Activity 1: Information sources

1. Before we jump in, we would like return to a question we asked yesterday. We will start with this question first for the rest of the board. Emotional Imagery: [show set of 18 images depicting different emotions] Looking at the images provided, please tell us which image best describes how you are doing today and which one best describes how your patient is doing. Use the text box to tell us why you picked this image and what is happening today with regards to the physical, social, and emotional impacts of lung cancer on you and your loved one.

2. On a scale of 1 to 10 (10 being high), how knowledgeable do you feel about SCLC? Please explain – what areas do you think you know a lot about and how did you learn it, what areas do you think you are missing information about?

3. Where or to whom do you and your loved one go to for information about lung cancer? (i.e. physician, medical website, blogs, Facebook communities, etc.)

4. What topics are of most interest to you when it comes to lung cancer? Select all that apply – information (e.g. on symptoms, side effects, treatments for SCLC, on being a caregiver, or other topics), assistance (e.g. help with caregiving tasks, help around the house), support (e.g. support networks, peer groups, mental health support, financial support), other. Please explain your answer in the text box.

Activity 2: Gathering information

5. We would like to understand the roles you and your loved one play in the gathering, management, and use of information about SCLC.

- Please describe the roles you and your loved one play when gathering information about SCLC.
- Please describe your dynamic on gathering and managing information about SCLC. This could be in terms of personalities, how the information is gathered and used.

Activity 3: Learning about treatment

6. In as much detail as you are able, can you please share the treatment(s) your loved one has been on in the past for SCLC and identify what their current treatment is?

- Tell us in detail about each treatment and the experience you and the person you care for had with it.

7. Was your ability to provide as a caregiver taken into consideration when your loved one was considering treatment options? How involved are you in the treatment decision-making process? Please expand.

Day 3: Physical Impacts of SCLC

Activity 1: Identifying the limitations

1. Emotional Imagery: [show set of 18 images depicting different emotions] Looking at the images provided, please tell us which image best describes how you are doing today and which one best describes how your patient is doing. Use the text box to tell us why you picked this image and what is happening today with regards to the physical, social, and emotional impacts of lung cancer on you and your loved one.

2. In your experience, what would you identify as the greatest physical challenge lung cancer has created for your loved one? Please expand to include details like: how often they experience the challenge, what it stops them from doing, their emotional state when faced with the challenge, approach to accommodations, etc.

Activity 2: Visualizing the limitations

3. For this next exercise we would like you to upload an image of an item (either take a picture or if you prefer, or download a similar image from the internet) that you associate with SCLC. It should not be medication. If taking a picture please ensure there is no personally identifying information on it.

- Please describe the object.
- How does this object make you think about SCLC?

- What emotions do you associate with this object? Please expand.

Activity 3: Managing the limitations

4. What are some regular challenges you face in feeling comfortable and confident as a caregiver? Please expand.

- Now imagine if the sky is the limit: what would better support you to overcome the challenges you mentioned above?

5. How have your roles as caregiver and loved one evolved since the diagnosis? Please expand.

Day 4: Social Impacts of SCLC

Activity 1: Impact on the social circle

1. Emotional Imagery: [show set of 18 images depicting different emotions] Looking at the images provided, please tell us which image best describes how you are doing today and which one best describes how your patient is doing. Use the text box to tell us why you picked this image and what is happening today with regards to the physical, social, and emotional impacts of lung cancer on you and your loved one.

2. What has the relationship with your loved one and their family/social circle been like?

- How have those relationships changed from receiving the diagnosis to now?
- How does that make them feel?

3. If available, please share a picture that captures a time in your loved one's life before the diagnosis. Please describe the picture and explain why you chose it.

- What does this image represent to you?
- What has changed since this image was taken?

Activity 2: Impact on your relationship

4. Do you feel you are able to maintain balance or boundaries between being a caregiver and your initial relationship to your loved one? (i.e. that of friend, spouse, parent, child) Why or why not? Please expand.

5. What systems of support do you or your loved one use on a regular basis? (patient support groups, online forums, etc.) Do you find this type of support helpful?

Day 5: Psychological Impacts of SCLC

Activity 1: Understanding the emotions

1. Emotional Imagery: [show set of 18 images depicting different emotions] Looking at the images provided, please tell us which image best describes how you are doing today and which one best describes how your patient is doing. Use the text box to tell us why you picked this image and what is happening today with regards to the physical, social, and emotional impacts of lung cancer on you and your loved one.

2. I want to understand how different areas of your loved one's life have been impacted by SCLC. Using the scales provided below, please divide the following areas in a way that represents how they have been impacted by lung cancer. The different sections can be different sizes, with the larger size representing a bigger impact on their life. All areas should add up to 100%. [Respondents scale on the following areas adding up to 100%: finances, physical well-being, emotional well-being (i.e. moods/feelings), psychological well-being (i.e. your identity and confidence), social life and other.]

- If you gave percentage to "Other", please explain what you have considered within this area and why you are including it.
- If asked the same question about how your loved one's cancer has impacted you, would the answer be the same? Why or why not?

3. Now I want you to imagine you could change one thing in each of the areas identified above: what would you change? Please explain your decision. As a reminder, the areas were finances, physical well-being, emotional well-being, psychological well-being, social life, and other.

Activity 2: Sharing the burden

4. I would now like you to imagine you are in a room, where you are completely free from judgement and prying eyes. This is a place where you keep your private thoughts, feelings, beliefs, and opinions. Looking around the room, could you please share one “secret” (e.g. thought, feeling, belief, opinion, emotion, etc.) about how the lung cancer has impacted your life, or made you feel. As a reminder, your identity will be kept private, and this secret will never be connected to you personally.

- How does this secret make you feel? Why?
- Why is this something you feel you cannot share?

5. Please write a letter of advice to someone who has just had a loved one diagnosed with small cell lung cancer who is about to take on a caregiving role to that person. As you write this, please consider what you wish you had been told when you learned about the diagnosis, the level of impact this will have on your relationship with your loved one and family, what you wish you could go back and do differently, and any hopes for the future.

Activity 3: Farewell

6. Reflecting on your experience answering our questions, is there anything that surprised you in your answers? Please explain.

7. Thank you so much for all your answers and insights, they are so helpful to us. Is there anything you think we need to know or understand about your condition, and the impact it can have?