

Appendix G. Focus Group Methods and Results

FOCUS GROUPS

A total of 36 stakeholders participated in the four focus group sessions, 2 with clinicians and 2 with patients. The participants were 20 clinicians, seven patients, six family caregivers, and three patient advocates. These stakeholders provided valuable input on study design, implementation, and content; refining data collection tools; recruiting and retaining research participants; identifying and selecting outcomes that patients with lung cancer notice and care about and that inform decision-making about which chemotherapy drugs will or will not be prescribed, and suggesting implementation and dissemination activities. (PC-1, PC-2, PC-3, PC-4)

We conducted four focus group sessions, two for obtaining the patients' perspective; and two to obtain the clinicians' perspective. The experienced focus group facilitator who led all four groups was the spousal caregiver of a patient who had died of lung cancer. Additionally, the facilitator has been actively involved as a patient advocate for cancer patients at the local, state, and national levels. We used focus group results to refine the formal protocol, revise the content and length of the data collection instruments to be used to answer Aim 1 and Aim 2. Also, we refined and revised data analysis plans, all to be more patient-centered and to appropriately contribute to our over-arching purpose of quality improvement of patient-centered clinical care of the patient regarding planning, implementation, and monitoring of advanced stage NSCLC chemotherapy. Specific data collection instruments created or refined as an outcome of focus group input included the baseline information sheet, interview scripts, questionnaires, the Distress Scale, and the Ranking Exercise. We also obtained input on how best to recruit and keep patients engaged throughout the study and garnered suggestions for dissemination of study findings. The focus groups were audio-recorded and transcribed verbatim

Transcripts from the focus groups were analyzed using NVivo10 qualitative data analysis software (QSR International Pty Ltd. Version 10, 2012). A thematic analysis was conducted through inductive processes.¹ Three researchers independently read the transcripts at least twice to familiarize themselves with the data. Following this process of immersion, they independently generated initial codes based on thematic content. Codes were then collated into emerging themes and sub-themes. After that, the three researchers met to resolve any ambiguity or disagreements on coding by discussion; themes and sub-themes were refined accordingly.²

Focus group participants provided input on a meaningful definition of chemotherapy treatment success. They described success as ranging from survival alone to elements of improved quality of life (QoL) or tied it to family and friends or important life events. Although all patients desired to be cured, most were cognizant of their prognosis and the limitations of medical care, given the stage of their disease. For some, treatment success meant going into remission, for others, it meant effective symptom management and having fewer side effects. Others equated success with being able to do normal day-to-day activities. For some patients and

family/informal caregivers, their preferred outcomes were better quality of life and more time with their families.

Examples of the patient-centric definitions of treatment success are captured in the following quotes: “Getting into remission and not having to come to this center every week.” “The ability to wake up in the morning and look forward to a normal day.” “I’d just like to be the woman that I was when I was 55...before this started...I want to be able to run to the barn!” “Being around to watch my grandchildren still grow up, that is success.”

Several other prominent themes were heard in the focus group discussions. One of these themes concerned coping with an advanced lung diagnosis. Both patient and clinician participants discussed how health care providers and the healthcare system could help patients cope with an advanced lung cancer diagnosis and spoke passionately about interactions with the healthcare system. Several volunteered examples of supportive and non-supportive relationships between patients and clinicians. For more on this subject, see the journal article that we published.³

Patients and their family/informal caregivers especially stressed building trust and a trustworthy and inclusive clinical environment that encouraged patient participation in both clinical treatments and research. Full disclosure of doctors and nurses of cancer and treatment options were valued. They also suggested strategies for the recruitment and retention of research participants, which included full disclosure of research expectations, building and sustaining patient trust and providing incentives.

Our study indicates that patients can successfully play active and engaged roles in clinical research, ranging from participant to partner and key informant. Judging from the enthusiasm of the focus group attendees, we found that many patients and family caregivers want to participate and be engaged in clinical research and see these activities as rays of hope as they are dealing with a serious, deadly disease such as advanced NSCLC. If they cannot help themselves, they want the research to help others.

References

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