Evaluating the user-perceived benefit of a virtual lung cancer patient education and support community: LVNG With Lung Cancer.

Mona L. Martin, Kristin Bucklen, Lise J. Hall, Beth Sandy, Dann Wonser, Genevieve de Renne; Evidera, Seattle, WA; AstraZeneca, Wilmington, DE; AstraZeneca, Gaithersburg, MD; Abramson Cancer Center, University of Pennsylvania, Philadelphia, PA; LVNG with Lung Cancer Ambassador and Advisor, Portland, OR

Background: The accessibility and quality of network support for people living with lung cancer (PLW) and their support partners (SP) can vary. Virtual platforms provide a unique opportunity for PLW/SP peer support and disease education; the challenge is to measure impact. Methods: Our aim was to determine user-perceived benefit of the Facebook based virtual community LVNG With Lung Cancer (https://www.facebook.com/LVNGWithLungCancerUS). Qualitative interviews were conducted with community members aged ≥18 yrs and living with lung cancer or actively supporting someone who had lung cancer. Also, inbound community comments (Dec 2015–Oct 2016) were retrospectively analyzed and grouped by similarity of content. Results: 18 PLW and 2 SP were interviewed (N = 20, saturation of concept met within the first 10). Mean yrs since diagnosis was 2.75 (range 0.08–17). Of the total expressions of benefit (n = 513) made during the interviews, 32% focused on increased health knowledge, with most participants calling out cancer information, good health behaviors, and coping strategies as key community benefits. Social impacts of the community accounted for 28% of benefit expressions; having a forum to share experiences and having a supportive environment were most frequently cited. An additional 18% of benefit expressions revealed that the community gives members feelings of empowerment, including feeling less alone (55% of respondents) and feeling inspired to help others (40% of respondents). Benefits received from community membership led to behavioral change in many respondents: 55% asked their doctor more questions, 50% shared helpful experiences with other members, and 35% took a more active role in their healthcare. In a notable example, an SP member said the community provided her with the knowledge she needed to address her symptoms and fears with her doctor, who was hesitant to biopsy because she did not meet typical risk criteria. Her self-advocacy was successful and ultimately led to an early lung cancer diagnosis. Results from the retrospective analysis of actual postings (n = 24,336; all unique users during evaluation period: n = 12,187) reflected the themes patients offered during interviews as important reasons to participate: 63% of postings were asking for or sharing cancer information, 98% provided emotional support and/or understanding, and 84% were inspirational/optimistic. Conclusions: This dual approach of assessing real-world impact of a virtual Facebook community provided insight into the benefit that members derive and highlighted the integral role of support groups in patient-centric care. Importantly, once members’ emotional and educational needs were met, they were empowered and/or inspired to take positive actions leading to better health behaviors and increased quality of life – an outcome that may have wider applicability for diseases beyond lung cancer. Research Sponsor: AstraZeneca.