

“Living with Cancer”

July 10, 2018, the Waseda Institute of Social and Human Capital Studies (WISH) held a lecture under the title of “Living with Cancer,” to which Mr. Shinsuke Amano, the Director of Japan Federation of Cancer Patient Groups and Group Nexus Japan was invited. His lecture was the second of such to call upon individuals with a range of standpoints, from the government officials, patients, and physicians, from among many stakeholders associated with health policy in Japan. Students of the Health Economics at Waseda (Subject instructor: Prof. Haruko Noguchi), Graduate School of Political Science, Public Management and the Graduate School of Economics, among various others, attended the lecture.

Mr. Amano developed malignant lymphoma when he was 27, and experienced treatments including large dose anticancer drugs and radiation therapy. The cancer returned two times, and since then his progress has been kept under observation; he is now involved in activities to support cancer patients, based upon his own experiences. He is a member of groups such as the Ministry of Health, Labour and Welfare’s Cancer Treatment Promotion Council, in which capacity he is closely involved in policy formulation, and works to improve legislation related to cancer, from the standpoint of a “patient.”

The onset of cancer may be discovered one day by chance, and treatment begins while one is feeling anxious regarding his or her work and future. As well as many cases where communication between the physician and patient is difficult, cancer patients are under pressure from decision-making, while suffering various worries and types of pain; there is the physical pain caused by progression of the cancer and side effects of treatment, psychological pain, such as anxiety, social pain from economic problems, and so forth. As such, Mr. Amano stated that there is another side to cancer, which is the difficulty in making rational decisions. He insists that the support that match the needs of the patients with respect to these pains is vital.

According to Mr. Amano, he has continued to strive to ensure that the activities of cancer patients are connected to efforts to build a society where they can life with peace of mind even after cancer has been developed. For example, there is a certain degree of significance in allowing patients who have experienced similar worries to interact with one another, to alleviate their psychological pain. Moreover, thanks to improved legislation, such as the establishment of the Cancer Control Act (2006) and its draft revision (2016), progress has been made in providing an environment which supports cancer patients. In terms of activities aimed at lessening the economic burden of cancer patients, although in previous years, patients paid in advance for any excess over their individual limit under the High-Cost Medical Expense Benefit system at the hospital’s service counter, on the other hand, thanks to efforts by patient groups like that of Mr. Amano et al., the economic pain has improved, as it is no longer necessary to pay in advance at the counter. As well, he is involved in a wide variety of efforts including the creation of guidelines for balancing treatment with one’s work life, support for cancer patients in remote areas and promotion of efforts to prevent passive smoking. In hospitals, cancer patients are regarded as “patients,” but after they have returned to their everyday

lives, many continue to receive treatment even while working, as they are now “ordinary citizens.” He believes that it is important for patients to be supported, for “rational consideration” of cancer patients to be recognized, such as flexible working that allows them to obtain time off from work, in units of hours, when they feel unwell, for example.

Mr. Amano said to bear in mind the fact that the results of activities aimed at saving the lives of cancer patients include the establishment and improvement of legislation and systems; when problems in the healthcare system or financing are discussed going forward, he wants everyone to listen carefully to the narrative of patients, such as their views and opinions, their pains and so forth, in combination with evidence such as the scientific basis behind their situation. This lecture about concrete activities aimed at a society which allows cancer patients to stand on their own two feet is a precious opportunity for us to think about healthcare policy, since it has very important contents which incorporate a shared human philosophy, a universal design rather than one focused on the patients alone.