Identifying the Social Support Needs of Young Cancer Patients in Japan

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Aim: Young patients under the age of 40 years are relatively rare, accounting for approximately 3% of all cancer patients. These patients have different problems and needs from older patients. The purpose of this study was to investigate young patients’ experiences and difficulties as well as their social support needs.

Methods: In this prospective study of young patients, a questionnaire and interview were used to assess the social and psychological reality and problems facing cancer patients under the age of 40 years. Besides, we evaluated common mental disorder by the patient health questionnaire (PHQ)-9. The study was conducted between January and September, 2013, in 3 cancer hubs and institutes in Japan.

Results: Of the 59 young cancer patients who were surveyed, 59% had breast cancer, 10% had gynecologic cancer, and 31% had sarcoma. Patients with recurrent cancer accounted for 31% of study participants. Additionally, 56% were married, 32% had children of preschool age or younger, 61% were employed, and 78% had a family history of cancer. The proportion of patients who were unemployed because of their incidence of cancer or experienced decreased sales at work was 61%. Meanwhile, 32% felt job insecurity and 49% were concerned about their family, although a higher trend was observed among patients with children (p = 0.054, p = 0.08 respectively). Of the 38 patients who were evaluated by PHQ-9, about 40% felt worthlessness and excessive guilt in more than several days in a past two weeks and about 10% had nearly every day. Most patients felt desolate because they could not find coeval patients with the same conditions. On the other hand, their awareness of the services offered by the social support center was low (29%); 75% of the patients had not used the center. Patients with a family history of cancer used the center significantly more (p = 0.025). Most patients obtained information from medical staff and the Internet.

Conclusions: Young cancer patients had a variety of social backgrounds and experienced different problems. However, their awareness and use of social support centers was very low. We plan to create an information to young cancer patients and peer support site on the Internet in the future.

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