

学位論文内容の要旨

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学位論文題名

Survivorship care after gynecological cancer: a qualitative study exploring experiences and perspectives of patients and specialists on post-treatment follow-up
(婦人科がん術後のサバイバーシップケア：術後フォローアップに対する患者と医師の意識に関する質的研究)

Background and Objectives: With an increase in the number of cancer patients and their survival rate owing to the development of effective treatments, the number of people living with and beyond cancer has been increasing. These people are now called “cancer survivors,” regardless of the length of time from their first diagnosis. As a result, a new research field related to cancer survivorship has emerged as the public and the medical community have become more concerned with the health and the lives of these survivors.

Still in its early years, cancer survivorship research has already illuminated lingering physical and psychosocial consequences left on cancer survivors. The research has also highlighted survivors’ information and care needs. As it became increasingly evident that the demand is high among the survivors for more care and support, proposals and policy initiatives such as establishing a system for providing survivorship care are now under discussions.

One of the issues that has been discussed is the question of how to provide post-treatment follow-up care. This issue directly addresses the concerns and needs of cancer patients and is a topic that has been researched in recent years motivated by the need to reduce the extra burden in medical institutions caused by the increase in the number of survivors.

However, evaluations of post-treatment follow-up from the view of providing patient-centered care have rarely occurred. Particularly in gynecological cancer, few studies have investigated the needs and expectations of the patients.

Moreover, in Japan, there has been a paucity of discussion about survivorship care. The purpose of this study is to explore the perceptions of survivors and specialists with regards to post-treatment follow-up care in gynecological cancer.

Methods: This study employs qualitative methodological approaches in order to examine experience, perceptions and expectations of both survivors and specialists in depth. The study used two types of data collection: focus groups and individual interviews. Focus groups were adopted to promote self-disclosure and active discussions among the patients through interactions within the groups. Twenty-eight gynecological cancer survivors who had received 1 to 10 years of post-treatment were

asked about their experience with and perspectives of follow-up care. For specialists, individual interviews were conducted to capture a variety of participant views. In total, 17 specialists were interviewed. All sessions were audio taped and transcribed.

The data were analyzed by following the steps of qualitative data analysis. Specifically, the following methods were used:

1. Thematic analysis was used to extract themes comprising of key components of survivors' perceptions about follow-up care.
2. Thematic analysis and event flow network techniques were used to elucidate the care-seeking behaviors of survivors suffering from adverse effects.
3. Grounded theory approach was used to extract themes comprised of the key components of the specialists' perceptions about follow-up and role-sharing with primary care physicians.

Results: Japanese gynecological survivors regarded follow-up as an opportunity for reassurance; however, they also wanted treatment for adverse effects and the opportunity to discuss their physical and psychological concerns they had experienced during the course of recovery. The expectations for communication and care were not fully met during follow-ups. Survivors sought care through specialty clinic visits when regular follow-ups did not fulfill their expectation for care of post-treatment adverse effects and when symptoms were not regarded as treatment-related. Lack of knowledge and inaccurate symptom interpretation delayed help-seeking, exacerbating symptoms. Specialists differed widely in terms of their attitudes towards patients' complaints and the care provision. This difference was caused by the specialists' perception about their responsibility in gynecological cancer follow-up and the time constraints that specialists felt. Specialists assumed primary care obstetrician-gynecologists could serve as potential partners and were open to the idea of transferring part of their responsibilities if a system for role-sharing were developed.

Discussion and Conclusion: The findings indicate that care of post-treatment symptoms and doctor-patient communication are just as important as recurrence management during follow-up from the perspectives of Japanese gynecological cancer patients. Their expectation for the care represents the patients' desire for their body and their life to recover and to be reconciled with their daily lives. This indicates that the failure to fulfill this expectation does not merely mean the prolongation of debilitating symptoms; it could also lead to a delay in their recovery from cancer. Although specialists' attitudes are keys in care provision, the findings from specialists' interviews suggest that the quality of care offered to a patient in follow-up can greatly vary based on the scope of responsibility defined by each doctor and the environment surrounding them. These observations suggest the importance of establishing guidelines for treating not only recurrence but also adverse effects and other supportive care, and for developing a system for role-sharing among health professionals that would support the recovery process of gynecological cancer survivors. Post-treatment follow-up care should be integrated in light of how to best assist gynecological cancer survivors seeking rapid recovery.