

**CCBIO Opinion**

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*the*  
*I*  
*in*  
*me*



# LIVING WITH OVARIAN CANCER: TRANSITIONS LOST IN TRANSLATION

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Ovarian cancer is a serious and highly lethal disease. For most women, it is a disease they have never heard of until they are diagnosed with it, making it difficult to understand and accept. Vague symptoms of illness suddenly become translated into a medical diagnosis, and although the disease will be treated, if not cured, the experience of illness will remain.

Women's experiences of and perspectives on illness and disease change along with their cancer trajectory. They experience losing their identity, not recognizing the *I in me*, not knowing who they are (Gissum et al., 2022). Women tell stories of being alone with the illness and disease, protecting their close ones from what they describe as torture, observing that the experience of illness at some point overcomes the disease itself. Being between illness and disease is to be lost in translation between the two worlds of ovarian cancer.

Medical advances in precision oncology, the increased reliance on genomic data, the use of biomarker testing, and patients' varying psychological responses have complicated the communication regarding precision oncology and personalized medicine. Although cancer is a medically definable physical disease, cancer –

like many other diseases that threaten life and health – has also been commonly used as a symbol. Symbols or metaphors are integral parts of everyday language and thinking. Metaphors may help patients control their thoughts and feelings about their illness and allow them to share their thoughts and feelings with others. In a patient–physician relationship, symbols of disease can help build a foundation for common clinical understanding. However, the horizons of patients and physicians are different, and the gap between the biomedical world and the *life-worlds of patients* is large. The more complex the scientific advances, the more space should be given to patients to voice what disease and illness mean to them.

In the last decade, there has been an increase in the number of clinical trials focusing on biomarkers that can prolong the lives of patients with ovarian cancer, but few trials have concentrated on how biomarkers can be used to establish individual follow-up care for ovarian cancer patients, and little attention has been paid to the ethical aspects of participating in such clinical trials. What patients want for their lives, how they want to manage their disease and their experience of illness, how they communicate their suffering, and how communication

issues may influence their decision-making and informed consent to participate in the trials should be crucial considerations in the era of precision oncology, with the goal of improving the quality of life of patients with ovarian cancer. ••

## References

Gissum, Karen Rosnes; Drageset, Sigrunn; Thomsen, Liv Cecilie Vestrheim; Bjørge, Line; Strand, Roger (2022). Living With Ovarian Cancer: Transitions Lost in Translation. *Cancer Care Research Online* 2(4):p e032, DOI: 10.1097/CR9.0000000000000032