

Effects of Written Information and Counseling on Illness-Related Uncertainty in Women With Vulvar Neoplasia

Silvia Raphaelis, Mag., RN, PhD, Hanna Mayer, Mag., RN, PhD, Stefan Ott, Dr. oec. HSG, Dipl.-Math. oec.,
Rene Hornung, PhD, and Beate Senn, PhD, RN

OBJECTIVES: To determine whether written information and/or counseling decreases illness-related uncertainty in women with vulvar neoplasia.

SAMPLE & SETTING: 49 women with vulvar neoplasia from four Swiss hospitals and one Austrian hospital.

METHODS & VARIABLES: A longitudinal, multicenter, randomized phase 2 study was performed. The written information group received a set of leaflets. The counseling group received five consultations with an advanced practice nurse (APN) from diagnosis to six months postsurgery that focused on symptom self-management, healthcare services, and decision making. Uncertainty was measured as a secondary outcome five times by the Mishel Uncertainty in Illness Scale.

RESULTS: Total uncertainty and the subscales of ambiguity, inconsistency, and unpredictability improved significantly over time within the counseling group but not within the written information group. In addition, counseling improved inconsistency over time, and total uncertainty, inconsistency, and unpredictability at distinct time points more efficiently than written information.

IMPLICATIONS FOR NURSING: Counseling can reduce illness-related uncertainty. APNs are valuable healthcare providers who promote women's self-management and may support them in becoming more familiar with illness-related events and common symptoms during this rare disease.

KEYWORDS vulvar neoplasms; female genital neoplasms; uncertainty; advanced practice nursing
ONF, 45(6), 748–760.

DOI 10.1188/18.ONF.748-760

Vulvar neoplasms, including vulvar intraepithelial neoplasia (VIN) as precancerous and vulvar cancer as cancerous cellular changes in the external female genitals (Bornstein et al., 2016), are rarely occurring conditions with an annual incidence of 1–7 per 100,000 in European countries and the United States (Akthtar-Denesh, Elit, & Lytwyn, 2014; HPV Information Centre, 2017; Lai et al., 2014; Meltzer-Gunnes et al., 2017). They have high recurrence rates and rising incidence rates and increasingly affect women younger than age 60 years (Akthtar-Danesh et al., 2014; Forman et al., 2012; Meltzer-Gunnes et al., 2017; Nooij et al., 2016).

The standard therapy consists of surgical procedures, which have been fundamentally improved during the past three decades (Gray, 2010; Kaushik, Pepas, Nordin, Bryant, & Dickinson, 2014). However, affected women still experience the treatment as disfiguring, particularly if it requires extensive resections of the labia or clitoris (Senn et al., 2011). The treatment leads, on average, to 20 biopsychosocial symptoms and difficulties in daily life one week postsurgery. One of the most prevalent psychosocial symptoms is uncertainty, occurring in about 83% of women (Senn et al., 2013).

This high uncertainty prevalence corresponds to the findings of several qualitative studies. They suggest that women with vulvar neoplasia experience uncertainty concerning the meaning of their disease; the disease trajectory; diagnostic results; and the meaning, likelihood, and variability of symptoms. In addition, they are uncertain about the potential for disease transmission, progression, and recurrence, as well as their reproductive and sexual capacities after treatment completion. The diagnostic process, therapy, and system of care are experienced as highly complex; sufficient information regarding the disease,