



Health Literacy

The role of health literacy in perceived information provision and satisfaction among women with ovarian tumors: A study from the population-based PROFILES registry



Mariëtte N. Verkissen^{a,b}, Nicole P.M. Ezendam^{a,b,*}, Mirjam P. Fransen^c,
Marie-Louise Essink-Bot^c, Mieke J. Aarts^b, Kim A.H. Nicolaije^{a,b},
M. Caroline Vos^d, Olga Husson^{a,b}

^a CoRPS – Center of Research on Psychology in Somatic Diseases, Department of Medical and Clinical Psychology, Tilburg University, The Netherlands

^b Eindhoven Cancer Registry, Comprehensive Cancer Center South (CCCS), Eindhoven Cancer Registry, The Netherlands

^c Department of Public Health, Academic Medical Center, University of Amsterdam, The Netherlands

^d Department of Obstetrics and Gynecology, St. Elisabeth Hospital, Tilburg, The Netherlands

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ABSTRACT

Objective: To assess the association of subjective health literacy (HL) and education with perceived information provision and satisfaction.

Methods: Women ($N = 548$) diagnosed with an ovarian or borderline ovarian tumor between 2000 and 2010, registered in the Eindhoven Cancer Registry, received a questionnaire including subjective HL, educational level, perceived information provision, and satisfaction with the information received. Multiple linear and logistic regression analyses were performed, controlled for potential confounders. **Results:** Fifty percent of the women responded ($N = 275$). Thirteen percent had low and 41% had medium subjective HL. Women with low HL reported less perceived information provision about medical tests, and were less satisfied with the information received compared to women with high HL. Low educated women reported that they received more information about their disease compared to highly educated women.

Conclusion: Low subjective HL among women with ovarian tumors is associated with less perceived information provision about medical tests and lower information satisfaction, whereas low education is associated with more perceived information provision about the disease.

Practice implications: HL should not be overlooked as a contributing factor to patients' perceived information provision and satisfaction. Health care providers may need training about recognizing low HL.

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1. Introduction

The provision of appropriate information is one of the most important aspects of the support for cancer survivors. Appropriate information provision, for example about the diagnosis, treatment, long-term effects, and care services, can result in informed decision making, improved treatment adherence, lower levels of distress, and higher satisfaction with care and information received [1–6]. Nevertheless, adequate information provision remains a challenge

in the field of cancer care. It has shown to be a common unmet need among cancer survivors in all phases of their disease [7]. Effective information provision requires an individualized approach that is tailored to the patient's needs, competences, limitations, and possible barriers to the use of health information [8]. Tailored information may lead to improved outcomes, such as better adjustment to treatment [9]. In general, patients want to be informed about their disease and its implications, regardless of whether this information is positive or negative [10,11]. However, specific information needs may depend on many individualized factors, including education and health literacy [12,13].

Health literacy (HL) entails people's knowledge and competences to access, understand, appraise, and apply health information [14]. After a cancer diagnosis, patients are often presented

* Corresponding author at: Comprehensive Cancer Center The Netherlands, 5600 AE Eindhoven, The Netherlands. Tel.: +31 40 2971616; fax: +31 40 2971610.
E-mail address: n.ezendam@iknl.nl (Nicole P.M. Ezendam).

with complex medical information regarding their disease and treatment [15,16]. Patients with low HL are at high risk of not being able to process the information they are provided. This puts them at risk for various negative outcomes, such as difficulty understanding the diagnosis and treatment recommendations, poorer adherence to medical advice, medication errors resulting from inability to read labels, and increased hospitalizations [17–19]. HL can be assessed using objective and subjective measures. Objective HL measures assess the individual's actual skills (e.g. reading and calculating), whereas subjective HL measures evaluate the individual's perceived skills (e.g. asking if he or she has difficulty understanding health information). Education is often thought of as a marker for HL. However, although HL and education are related to each other [20], they need to be understood as distinct concepts [21,22].

Despite the increased recognition of the importance of both information provision and HL in cancer care, research on the role of HL in information provision to cancer patients is limited. Previous studies have examined the relation between breast cancer patients' HL and information-processing styles and preferences [23], breast cancer patients' HL levels compared to the level of written patient educational materials provided to them [24], and the relation between cancer patients' HL and self-reported information needs [22,25]. To our knowledge, however, no studies have focused on the relation of cancer survivors' HL with perceived information provision and satisfaction with the information received.

The present paper describes an explanatory study focusing on the additional effect of HL over education on information provision in a population-based sample of Dutch women with ovarian cancer and borderline (low malignant potential) ovarian tumors (BOT). Cancer of the ovary is one of the most common gynecologic malignancies, whereas BOT are relatively uncommon. In the Netherlands, about 1300 cases of ovarian cancer and 150–200 cases of BOT are diagnosed annually [26,27].

The main purpose of this study was to investigate the association between HL and perceived level of information provision and information satisfaction, controlling for educational level. In order to distinguish between the potentially different effects of HL and education, we also evaluated the association between educational level and perceived level of information provision and satisfaction. Given that patients with inadequate HL tend to be passive during physician–patient communication and

ask few questions during consults [28,29], we hypothesized that lower HL would be associated with less perceived information provision among women with ovarian tumors. In the limited time that physicians have with their patients, they may not be able to tailor the information according to their needs. We therefore hypothesized that lower HL would be associated with less satisfaction with the information received. Finally, based on previous research indicating that patients with lower educational levels generally feel less confident and are more likely to be passive in interactions with physicians [30], we hypothesized that lower education would also be associated with less perceived information provision and less satisfaction with the information received.

2. Methods

2.1. Setting and participants

This study is part of a population-based survey among women with ovarian cancer and BOT registered within the Eindhoven Cancer Registry (ECR). The ECR collects data of all individuals newly diagnosed with cancer in the southern part of the Netherlands [31]. All women diagnosed with ovarian cancer or BOT between January 1, 2000 and July 1, 2010 as registered within the ECR were eligible for participation ($N = 1442$; Fig. 1). Deceased patients were excluded by linking the ECR with the Central Bureau for Genealogy. Ethical approval for the study was obtained from the Medical Ethics Committee of St. Elisabeth Hospital, Tilburg, the Netherlands (no. 2011.129).

2.2. Data collection

Data collection took place in 2012. Along with a paper questionnaire, patients received a letter from their specialist explaining the survey and an informed consent form. Non-respondents were sent a reminder letter and questionnaire within 2 months. Patients were asked to send the informed consent form and questionnaire back to the researchers in a pre-stamped envelope.

The PROFILES (Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship) registry was used to organize the data collection. PROFILES is an infrastructure for the study of the physical and psychosocial impact of cancer and its treatment from a dynamic, growing population-based cohort of

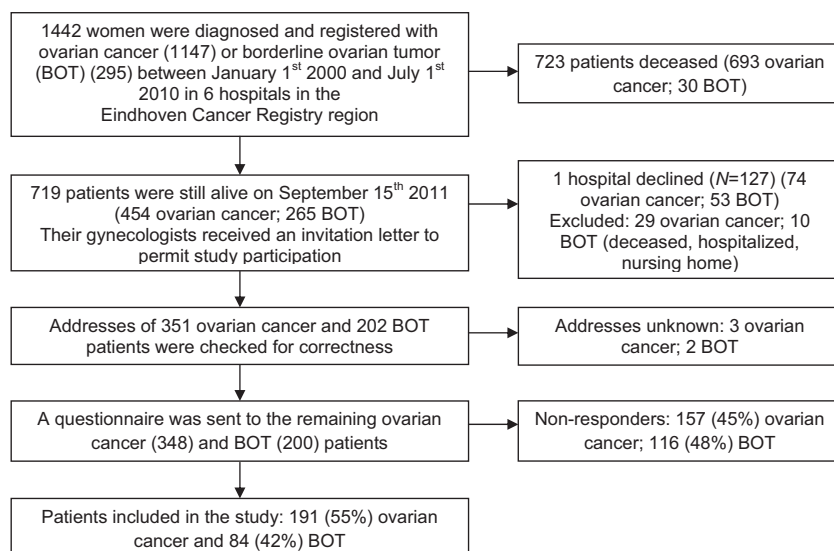


Fig. 1. Flowchart of the data collection process.

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