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Original article

The effect of an online support group on patients' treatment decisions for localized prostate cancer: An online survey

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Abstract

Objective: To analyze the effect of an online support group (OSG) on the final treatment decision for localized prostate cancer.

Methods: We performed a cross-sectional descriptive study of the largest German prostate cancer OSG between July and October 2013. The online survey comprised 127 questions covering sociodemographic and disease-related information, decision-making habits, health-related quality of life, distress, depression, and anxiety. The primary outcome was to measure the effect of an OSG on the final treatment decision.

Results: We analyzed the completed questionnaires from 686 patients with prostate cancer, 200 (29.2%) of whom revised their initial treatment decision. After revising their decisions, these patients more frequently underwent external beam radiation therapy (44.5% vs. 36.4%, $P = 0.048$) and active surveillance (10.5% vs. 3.7%, $P < 0.001$) and less frequently underwent radical prostatectomy (52.5% vs. 74.9%, $P < 0.001$). Engaging longer in the OSG, demanding a more active role in the decision-making process, and participating in a conventional support group were independently associated with revision of the initial treatment decision.

Conclusions: Of all patients participating in the OSG, 29.2% revised their initial treatment decision. We estimate that this phenomenon may affect 17,000 patients with prostate cancer in the United States of America every year. This finding highlights the importance of OSGs for the health care system. The patient's desired degree of involvement in decision-making should be routinely clarified to adjust counseling accordingly.

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Keywords: Online support group; Decision-making; Peer-to-peer support; Bias; Prostate cancer

1. Introduction

Patients with chronic and oncological diseases increasingly use the Internet as a source of patient information and support [1,2]. In addition to the general development of the “social web,” the demand for online support appears highest for stigmatizing and devastating diseases, including prostate cancer [3–5]. This evolving effect of modern media appears inevitable and offers a significant opportunity to improve the health care system and the physician-patient relationship by encouraging participatory decision-making [6,7].

Localized prostate cancer presents a good example for exploring the opportunities and risks of modern media for patient empowerment: it demands complex decision-making with a high level of patient involvement [8,9]. Several available treatment options might be equally effective while

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causing different spectra of side effects [10]. Primary treatment options include radical prostatectomy (RP), external beam radiotherapy (EBRT), brachytherapy, active surveillance, and watchful waiting [10]. Economic factors and the involvement of urologists, radiation oncologists, and other specialists further complicate the decision-making process [11].

The process of treatment decision-making may be described as a complex interplay of 3 domains comprising physicians, patients, and contextual factors [12]. A comprehensive systematic review by Tariman et al. [12] describes these factors in the context of the most relevant theoretical models of decision-making. Modern media influence all 3 domains, particularly patient factors such as personal beliefs and values, decisional control preferences, previous health-related experience, social structure, and personal factors. Among these, social support plays a major role in decision-making for localized prostate cancer; moreover, the importance of online resources has become increasingly recognized [13]. The importance of the Internet was underscored recently by a study that randomized 494 men with localized prostate cancer to the use of a decision support system vs. usual care [14]. Only prior Internet use and perceived preparation for decision-making significantly predicted 6-month decision satisfaction [14]. Whether Internet use also affected the treatment modality that patients finally chose remained an open question. This finding exposes a general knowledge gap because the study endpoints were generally limited to descriptions of the surrounding conditions [2,15,16] and subjective perceptions [16,17] of decision-making.

Online support groups (OSGs) represent one of the most widespread interactive Internet resources; they enable patients to discuss personal information anonymously and provide patients with information, advice, and emotional support [13,17]. Quantifying the effects of this peer-to-peer counseling is difficult, and well-designed comparative studies are lacking; specifically, no such data exist for patients with prostate cancer. For breast cancer, an uncontrolled longitudinal study demonstrated reduced depression and improved reactions to pain in 32 patients [18]. Beyond investigating patient-reported outcomes, determining the possible effect on final treatment decisions is imperative. Owing to the growing relevance of patient empowerment and shared decision-making, OSGs might directly affect health care delivery, health economics, and the physician-patient relationship, adding significant epidemiologic and economic weight to understanding OSGs' effects on treatment decisions. The discourse within OSGs might stimulate patients to reconsider previous recommendations, and a share of patients might ultimately revise their choice. The size of this effect is unknown; however, at least modest evidence exists from a recent systematic review demonstrating that OSGs may be effective in changing participants' behavior [19]. To the best of our knowledge, no reliable data exist to date on the influence of OSGs on patients' actual treatment decisions.

Our cross-sectional descriptive study analyzed an OSG's effect on final treatment decisions for localized prostate cancer through an online survey within the largest German OSG to identify how many and which participants revised their initial treatment decision after consulting the OSG.

2. Methods

2.1. General conduct

An online survey open from July to October 2013 was offered to participants in the largest German prostate cancer OSG present since June 2000. To widen the scope of our study, we did not apply a specific theory of decision-making a priori [12]. We followed the Checklist for Reporting Results of Internet E-Surveys [20].

2.2. OSG structure

At the time of data collection, 3,357 users were registered with more than 70,000 postings. The numbers of users and postings have nearly doubled within the past 5 years [13]. The OSG is freely accessible with use of the German language as the only prerequisite. This group is maintained by the umbrella organization of regional prostate cancer support groups in Germany (Bundesverband Prostatkrebs Selbsthilfe e.V.), a member of “Europa Uomo—The European Prostate Cancer Coalition” (http://www.europa-uomo.org).

2.3. Study design

The survey contained 127 questions within a dynamic questionnaire (Appendix 1). The deciding question for group allocation was “Has your treatment decision changed through the use of the discussion board?” Three options were provided: “Yes,” “No,” and “Not specified.” We defined “Yes” to indicate a change of the initial treatment decision. Participants who chose “No” or “Not specified” were included in the comparison group without a change of the initial treatment decision.

To compare the participants who revised their decisions and those who did not report a change, the survey contained 12 sociodemographic, 16 disease-related, and 64 psychological questions complemented by 35 questions on decision-making and information-seeking habits.

Regarding the structure of the German education system, we defined education status according to the duration of schooling as low or medium (≤ 11 years) vs. high (≥ 12 years). The psychological questions consisted of validated instruments for measuring quality of life (EORTC QLQ-C30 and the prostate module PR25) [21], depression and anxiety (PHQ-4 [22]), and the distress thermometer [23].