

Evaluation of a visit preparation intervention implemented in two rural, underserved counties of Northern California

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Abstract

Objective: Evaluate satisfaction with visit preparation at three rural resource center sites.

Methods: The resource centers sent eight employees and two volunteers for training at UCSF in Consultation Planning (CP). CP is a service to help patients make a list of questions before seeing their doctors. Researchers used multivariate ordered logistic regression analysis to investigate the variation in satisfaction among 99 CP Clients served by the resource centers in 2003.

Results: Sixty-seven CP Clients who completed surveys were highly satisfied (mean = 8.67, standard deviation (S.D.) = 1.85, range = 5–10). Variation in satisfaction was associated only with whether or not the CP Provider was a breast cancer survivor serving a breast patient ($p = 0.005$). Satisfaction was not associated with CP Client demographics; type of upcoming medical visit; or CP Provider age, remuneration status, nursing background, and volume of CP Clients.

Conclusion: Community-based resource centers have implemented CP to the satisfaction of their clients. Further research should expand the delivery of CP to more underserved members of the community and evaluate its acceptability and impact. There may be a therapeutic alliance formed when survivors provide CP to newly diagnosed patients.

Practice implications: CP should be considered by patient support programs wishing to expand their client services to include visit preparation.

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1. Introduction

Cancer patients face a potentially life-threatening diagnosis. Before, during, and after treatments, most patients consult a variety of specialists: surgeons, oncologists, radiation oncologists, plastic surgeons, and others. Thus, patients and physicians communicate during these important meetings, exchanging information on various

topics thought by one party or the other to be significant in advancing their goals [1].

A recent US National Cancer Institute systematic review confirms that health professionals are the preferred source of information among cancer patients, and reveals 10 major topics where patients express the need for information: treatment-related; cancer-specific (e.g. diagnosis); rehabilitation; prognosis; coping; interpersonal/social; body image/sexuality; surveillance and health; financial/legal; and logistical/medical system-related [2].

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Are these information needs being met in cancer consultations? A Canadian National Cancer Institute systematic review concludes that “Cancer patients continue to have unmet communication needs, a significant proportion of which pertain to unfulfilled needs for disease and treatment-related information, including extent of disease, prognosis, treatment alternatives, treatment intent, and treatment side effects . . . Physicians have the tasks of discerning what information to impart to patients, the extent to which they will involve patients in treatment decision making, and the degree to which they will communicate with patients about their emotional status and other non-medical aspects of quality of life.” [3].

In order to help patients and physicians meet these information communication needs, researchers have created a class of patient-oriented visit preparation interventions. Visit preparation research has been divided between interventions that are self-administered by patients and those that involve coaching or guidance from an investigator or research associate [4].

Roter pioneered the in-person approach to visit preparation prior to 1977. She found patients asked more questions and kept more appointments when coached with a prompt sheet reviewing “possible questions in the areas of etiology, duration, severity, and prevention of illness” [5]. In 1980–1981, Greenfield et al. used each patient’s medical record as a prompt sheet to stimulate questions. They found significant effects on functional outcomes as well as satisfaction, participation, and knowledge, compared to a control group given information in person [6]. In 1988 they reported on a follow-up study with 73 diabetes patients randomized to similar arms, replicating their previous study results as well as reporting that improved participation led to improved blood sugar control [7]. In 1994, Butow and co-workers began reporting on a series of randomized controlled trials, finding that a prompt sheet of frequently asked questions generally improved the quantity and quality of questions asked in consultations [8–10].

A recent systematic review summarized 13 more randomized, controlled trials of in-person, patient-oriented visit preparation up to the year 2000 [4] and concluded that such “interventions directed at patients can be successful in increasing patient participation.” The authors of a similar review concluded, “Trial evidence suggests that a range of approaches can achieve changes in this [patient–provider] interaction and some show promise in improving patients’ health. In terms of practice there are strong justifications unrelated to evidence-based medicine for adopting a collaborative approach to the medical encounter, such as, for example, patient preferences and moral imperatives” [11].

Have these visit preparation interventions in fact been adopted? We performed a forward citation search for the most relevant articles cited in the above reviews [5–10], finding 1269 titles. We then searched these titles for the stems “adopt,” “field,” “implement,” and “practice.” We failed to generate any obvious references describing the

routine integration into clinical care of these visit preparation interventions. This suggests that implementations of these interventions may be underemphasized compared to follow-on research. This article therefore contributes to the literature by reporting on the field evaluation of an in-person visit preparation intervention called Consultation Planning (CP), implemented in a rural, medically underserved community setting by non-profit resource centers.

2. Methods

2.1. Objectives

The specific aims of the present study are: (1) to determine whether patients receiving CP from rural, community-based resource centers in Northern California were satisfied with the service and (2) to explore the variation in patient satisfaction according to co-variables describing the location, provider, and recipient of the CP service.

2.2. Intervention

CP was developed by the first author as part of his doctoral dissertation at Stanford University [12,13], in response to the needs of local breast cancer patients [14]. CP was initially evaluated at Stanford, UCSF, and the Palo Alto Community Breast Health Project and was found more satisfying and effective in reducing communication barriers than an active listening control [13,15,16]. CP consists of a structured interview that prompts a patient to generate the agenda for an upcoming meeting with a physician [17]. A trained CP Provider uses a prompt sheet to help patients formulate their questions and concerns. The number, order, and wording of prompts are subject to annual revisions based on feedback from researchers, CP Providers, and patients. Table 1 shows the most recent edition.

The CP Provider documents the patient’s questions and concerns in a word-processed Consultation Plan for the patient to use in the upcoming meeting with a healthcare provider. Copies of the Consultation Plan are also offered, at the patient’s discretion, to family members and healthcare providers. Table 2 provides a de-identified example of a recent Consultation Plan created for a UCSF patient. Other reports have examined the implementation of CP at UCSF and at the Palo Alto Community Breast Health Project, where CP originated [18,19]. The present study concerns itself with the diffusion of CP to three other sites in Northern California.

2.3. Study design, procedures, and settings

This is a retrospective descriptive study of the satisfaction reported by rural patients upon receipt of CP. Between 2000 and 2002, based on word-of-mouth exposure to the CP service at UCSF, three community resource center sites from

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