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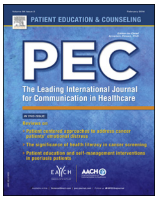

Communication Study

Does source of patient recruitment affect the impact of communication on trust?

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A R T I C L E I N F O

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Objectives: To investigate how comparable outcomes of medical communication research are when using different patient accrual methods by comparing cancer patients organization members with outpatient clinic patients.
Methods: In an experimental video-vignettes study, the impact of oncologist communication on trust was tested. Background characteristics (socio-demographics, trait anxiety, health locus of control and attachment style), reported trust, and the impact of communication on trust were compared between the two groups.
Results: Cancer patient organization members ($n = 196$) were younger and higher educated than clinical patients ($n = 148$). Members felt more personal control over their health ($p < .01$) but were also more anxious ($p < .05$). They reported lower trust in general health care ($p < .05$), in their own oncologist ($p < .001$) and in the oncologist in the videos ($p < .05$). The impact of oncologist communication on trust was similar for both groups.
Conclusions: Despite considerable differences in trust levels, both groups appear equally affected by oncologist communication. Thus, although including cancer patient organization members may impact the generalizability of some findings, using these participants to investigate communication appears justified.
Practice implications: Cancer patient organization members may regard their oncologist more critically. Research including both members and patients recruited through hospital clinics could take group membership into account as a possible confounder. Nonetheless, communicating competence, honesty and caring may benefit the relation with these patients similarly as with other patients.

1. Introduction

Approaching real patients for participation in medical communication research is sometimes difficult [1]. To facilitate patient recruitment, researchers frequently refer to patient associations, self-help groups or advocacy groups (see for example [2–8]). Members of such groups are known to be willing and motivated to participate in research. However, they may not always be representative of the average patient. Indeed, researchers who sampled patient support group members have frequently discussed a potential lack of representativeness as a limitation of their studies (e.g., [4,6]).[1]

Only a small percentage of all patients are represented in patient organizations. For example, on average 5% of Dutch cancer patients is a member of a patient organization [11]. Members of support groups have been found to be more likely highly educated, female, white and middle class than others [12–14]. Moreover, they were more agreeable, employed more active coping strategies

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[1] The terms ‘patient support group’, ‘patient organization’ and ‘patient advocacy groups’ are often used interchangeably. In essence, however, the term ‘support group’ refers to active interventions aimed at individual patients [9]. The terms patient organizations and advocacy groups refer to the organizations that primarily promote patients’ collective interests [10]. Thus, a patient organization may organize support groups as one of their activities. We will refer to ‘patient organizations’ throughout this article, adapting our phrasing when quoted literature explicitly refers to ‘patient support groups’.

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and felt more control over their disease. On the other hand they were found to feel more anxious and distressed [14].

If such socio-demographic and personality characteristics influence patients' perception and evaluation of communication, selection bias might occur when participants for research of medical communication are recruited through patient organizations.

Empirical research on such selection bias is surprisingly scarce. To date, literature has mostly focussed on comparing between research participants (volunteers, members of patient support groups) and non-participants, allowing only a comparison of general background characteristics [15,16]. Investigating whether patient selection influences relevant outcome measures is only possible when both patient organization members and non-members participate in research. This was the case in a (non-communication) study investigating selection bias, comparing quality of life outcomes of members from a patient organization for sarcoidosis with a random sample of non-member sarcoidosis patients [17]. Results indicated that the patient organization members reported lower quality of life and more physical symptoms than non-members. Comparable studies in the field of physician–patient communication, however, appear nonexistent.

We performed a study on the effect of oncologist communication on patients' trust [39]. In this study, we experimentally investigated whether oncologist's enhanced expression of medical competence, honesty and caring communication induced higher trust in the oncologist. After viewing a video of an enacted medical consultation, patients' trust in the observed oncologist was assessed [39]. Participants were accrued through various Dutch cancer patient organizations as well as oncology outpatient clinics. Including both members and non-members created a unique opportunity to compare the two groups. The aim of this study was therefore methodological: to estimate if cancer patients accrued through patient organizations differ from patients accrued through hospital outpatient clinics on (1) socio-demographic and personality characteristics, (2) trust levels, and (3) the impact of oncologist communication on trust. As such, this study provides insight into the impact of patient accrual choices patient accrual on patient-reported outcomes.

2. Methods

Video vignettes, i.e., videotaped scripted medical consultations, were created (see below). After composing a basic vignette, three elements of oncologist communication were systematically varied on two levels (standard vs. enhanced): conveyance of *Competence*, *Honesty*, and *Caring* ($2 \times 2 \times 2$ factorial design). Participants were randomly assigned to view two out of eight versions of the video vignette. Study design, video-vignettes development and procedure have been described in detail in [39].

2.1. Sampling

All participants had to be at least 18 years old, have acceptable proficiency of Dutch, and being in treatment or follow-up with an oncology specialist presently or previously. Patients were informed that the study concerned the relation between patient and oncologist.

2.1.1. Cancer patient organization members (CPO members)

Members of 15 different cancer patient organizations were invited to participate through printed and online advertisements of the organizations' journals and websites. Interested members could self-apply through telephone, e-mail or regular post.

2.1.2. Clinical patients

Patients who had been treated or were currently being treated for cancer were approached through four oncology departments of one academic and one non-academic hospital. Patients from the academic hospital (surgery and radiotherapy) received an invitation letter from the researchers, asking them to self-apply through an enclosed reply card, by phone, or by e-mail. Non-respondents were reminded three weeks later. Patients could also indicate their reasons for refusal on a reply card. Patients at the non-academic, rural hospital (surgery and medical oncology) were approached by their nurse–practitioner. The researchers received contact details of possibly interested patients and contacted them by phone.

2.2. Measures

Socio-demographic characteristics were assessed using open-ended (age) and multiple-choice (gender, education) questions. Patients were asked to indicate the time since diagnosis in months, cancer site, and whether they were still in active treatment. Trust in health care in general was assessed by asking: '*How much trust do you have in the current Dutch health-care system?*' (*very little trust* = 1 to *a great deal of trust* = 5) [18]. Patients' trust in their own treating oncologist was assessed using the well-validated *Trust in Oncologist Scale* (TiOS) [19,20]. The *TiOS* consists of 18 statements (*completely disagree* = 1 to *completely agree* = 5). An example of a question is '*Your doctor strongly cares about your health*'. An overall score is obtained by averaging the responses. Reliability of the scale was good in this sample ($\alpha = .94$). Trust in the observed oncologist was also assessed with the *TiOS*, adapting the phrasing to refer to the observed oncologist, instead of patients' own treating oncologist ($\alpha = .82$). Attachment was assessed using the *ECR short form* [21], which measures attachment avoidance (6 items) and attachment anxiety (6 items) (*completely disagree* = 1 to *completely agree* = 7). Reliability was acceptable ($\alpha = .74$ for attachment avoidance and $\alpha = .60$ for attachment anxiety). Patients' external health locus of control was assessed using the Dutch version of the *Powerful Others* subscale of the 5-item *Medical Health Locus of Control* scales (PO-MHLC) (*completely disagree* = 1 to *completely agree* = 6) [22,23]. Reliability was good ($\alpha = .83$). State anxiety was assessed on the 20-item *Trait* subscale of the *State-Trait Anxiety Inventory* (STAI) (*almost never* = 1 to *almost always* = 7) [24]. Reliability was high ($\alpha = .92$).

2.3. Analysis

Handling of missing data and manipulation checks are described in [39]. Comparisons between the two groups (CPO members vs. clinical patients) were made with regard to socio-demographic, disease and personality characteristics using χ^2 tests and independent *t*-tests (Question 1). Effect sizes for *t*-tests are reported as r^2's, ($r^2 = .01$ small, $r^2 = .09$ medium, $r^2 = .25$ large) [25,26]. The main effect of patient group (CPO members vs. clinical patients) on trust in the observed oncologist (Question 2), as well as the moderating effects of patient group on the relation between communication manipulations and trust (Question 3) were examined using stepwise random intercepts multilevel analyses. This analysis accounts for the multilevel structure of observations (level 1) nested within patients (level 2), as all patients viewed two different videos.

For multilevel analysis, power analysis using G*Power version 3.1.5 [27] was performed. We aimed to test 10 effects. Using an *alpha* of .05, for a 95% power to detect effects with a medium effect size of Cohen's $F^2 = .15$, at least 172 observations would be required [26]. To account for the fact that two observations were nested within each patient, the number of independent observations was calculated. Therefore, the required sample size was multiplied by 1+ the presumed correlation between *TiOS* scores of observations 1 and 2 ($r_s = .70$) [28]. This yielded a minimum sample size of 292 observations. Our baseline model, Model 1, included all previously