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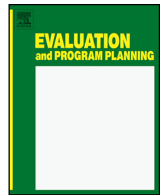

Patients and caregivers costs for colonoscopy-based colorectal cancer screening: Experience of low-income individuals undergoing free colonoscopies☆

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ABSTRACT

Many studies have documented barriers to colorectal cancer screenings. However, there is lack of comprehensive information on the time and costs borne by low-income patients and the persons accompanying the patient (caregiver) for colonoscopies in the United States. We surveyed patients in three health clinics in Philadelphia retrospectively who had undergone free colonoscopies in the previous 18-month period. Participants were asked questions about time and out-of-pockets expenses for themselves and their caregivers. Even when colonoscopies were free to the patient through Colorectal Cancer Control Program funded by the Centers for Disease Control and Prevention, the patient and caregivers still incurred costs in relation to preparing for, undergoing, and recovering from a colonoscopy. These costs can be substantial and may account for some of the low colorectal cancer screening rates especially among the low-income populations. Patients' and caregivers' costs need to be considered when designing and implementing colorectal cancer control programs.

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1. Introduction

Colorectal cancer (CRC) screening has been shown effective in reducing mortality from CRC (Zauber et al., 2008). The U.S. Preventive Services Task Force recommends CRC screening for average-risk adults aged 50–75 years using high-sensitivity fecal based test annually, sigmoidoscopies every 5 years with fecal-based testing every 3 years, or a colonoscopy once every 10 years (U.S Preventive Services Task Force, 2008). Yet the take-up rate for any CRC screening remains low: less than 60% of men and women aged 50 and older are up-to-date with CRC screening (Sabatino, White, Thompson, & Klabunde, 2015). Among uninsured, fewer than 1 in 4 received the recommended screening for CRC (Sabatino et al., 2015). In an effort to increase CRC screening rates, the Centers for Disease Control and Prevention (CDC) established the Colorectal Cancer Control Program (CRCCP) in 2009. The CRCCP funded 29 grantees, both states and tribal organizations, for a period of 6 years to support screening provision and promotion activities.

Many studies have documented barriers to cancer screenings in general and CRC screenings in particular. The barriers include low levels of education, language or communication challenges, low socioeconomic status, and lack of insurance coverage (Gimeno Garcia, 2012; Heitman, Au, Manns, McGregor, & Hilsden, 2008; Subramanian, Klosterman, Amonkar, & Hunt, 2004). Cost has also been cited as a barrier (Jones, Devers, Kuzel, & Woolf, 2010; Klabunde et al., 2005). A report conducted by the National

Abbreviations: CDC, Centers for Disease Control and Prevention; CRC, colorectal cancer; CRCCP, Colorectal Cancer Control Program; FOBT, fecal occult blood test.

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Institutes of Health's Center to Reduce Cancer Health Disparities detailed three main cost categories: direct, indirect, and intangible costs. Direct medical costs are those related to the provision of clinical services, such as facilities and clinician fees, and cost of medical supplies including bowel prep products. Direct nonmedical costs include all costs not directly related to medical services such as transportation and child care costs. Indirect costs are also nonmedical costs and relate to cost of time lost from work (lost productivity cost) by the patient and caregivers as a result of their commitment to the clinical procedure. Intangible costs include costs associated with adverse effects from the clinical procedure on the quality of life (Center to Reduce Cancer Health Disparities (U.S.), 2007).

Few studies have examined the nonmedical costs (which includes direct nonmedical cost and indirect cost) of screening for CRC (Frew, Wolstenholme, Atkin, & Whynes, 1999; Heitman et al., 2008; Henry, Ness, Stiles, Shintani, & Dittus, 2007; Jonas, Russell, Sandler, Chou, & Pignone, 2007; Yabroff, Borowski, & Lipscomb, 2013). In a recent review, Yabroff and colleagues found that of 65 international studies published in 2000–2010, only 18 addressed costs for patient or caregiver time, travel, or lost productivity (Yabroff et al., 2013). These studies did not specifically focus on CRC screening, and they were mostly related to cancer care. There is no study to date that provides a comprehensive assessment of the cost to low-income patients and those who accompany them for colonoscopy screening (caregivers) in the United States. These costs can be an important barrier for undergoing colonoscopy screening.

In this study we examine the costs borne by patients who underwent CRC screening and their caregivers at three community health centers in inner-city Philadelphia, Pennsylvania. These clinics all participated in the CRCCP program in Pennsylvania and offered free colonoscopy screening. This article provides an important contribution to the literature as it evaluates a potentially significant barrier to CRC screening among the disadvantaged low-income population who are either uninsured or underinsured.

2. Methods

2.1. Questionnaire development

A questionnaire was developed and pretested that captured patient sociodemographic characteristics as well as time requirements and expenses incurred through the CRC screening process. In developing the questionnaire, we reviewed existing surveys and the published literature in order to use standardized questions where possible. Questions included time spent traveling, time spent waiting at the physician office, and time spent undergoing procedures. The questionnaire also collected details on the travel expenses for precolonoscopy visits, the colonoscopy procedure, and postcolonoscopy visits; bowel prep product and childcare expenses. Patients were also asked about how they traveled to the visits (e.g., private or public transportation) and whether they had someone to accompany them. Questions about the caregiver work status and position were asked to determine their costs incurred in assisting the patient. In this manuscript, "caregivers" refer to spouses, family members, and friends who accompanied the respondent to any colonoscopy appointments. Although colonoscopies were provided free through the CDC's CRCCP to all patients; in some instances patients had to pay a proportion of the cost for bowel prep products. This would constitute direct medical cost and was captured when relevant.

Once the questionnaire was drafted, it was pretested to finalize wording of the questions and order of presentation. This study was approved by RTI International's institutional review board and the Office of Management and Budget (OMB Control No. 0920-0963).

2.2. Data collection approach

One of the grantees of the CDC's CRCCP was Pennsylvania, which funded clinics to provide colonoscopies at no cost to patients. The project team partnered with three funded community health centers in Philadelphia to conduct the study. We used a convenience sample of average risk individuals 50–74 years who has received CRCCP funded colonoscopy screening within an 18 month period (June 2012 to November 2013). Our goal was to complete 150 questionnaires to ensure that adequate sample was available for this exploratory analysis. Medical assistants reviewed patient charts and clinical records to identify patients who underwent CRCCP funded screening colonoscopies. The medical assistants then contacted the selected individuals in person (if they has an upcoming appointment at the center) or via telephone to explain the study and ask whether they would participate. After obtaining patient consent, the medical assistants scheduled an in person visit to complete the questionnaire. All patients who were approached, agreed to participate and there were no refusals. Patients received a $20 gift card as incentive. All questionnaires were administered in English and data collection occurred during November–December 2013. A total of 150 questionnaires were administered in the three sites and deidentified data was compiled for analysis.

2.3. Data analysis

Demographics and work status information were summarized for patients and caregivers. We categorized the time and cost into four activity groups: attend a precolonoscopy office visit, prepare for a visit, attend a colonoscopy visit, and attend a postcolonoscopy office visit. The amount of time spent for each visit was assumed to be the same for the patient and the caregiver (if the patient was accompanied).

We report the actual time and cost estimates in 2013 U.S. dollars for persons who incurred them, and the mean across all questionnaire respondents. To calculate the cost of lost time attending colonoscopy-related visits (opportunity cost), we used wage information ($11.68/h for respondents and $14.97/h for the caregivers) from the Bureau of Labor Statistics and took a weighted average based on occupation reported by those working. This ensures that the time of all individuals (those employed and those not in formal employment) is accounted for (Bureau of Labor Statistics, 2015). Also, if respondents did not report costs to travel to doctors' offices, we assigned mileage costs of 23 cents per mile, based on Internal Revenue Service mileage allowance for medical purposes, and estimated a distance traveled of 10 miles each way. We learned that clients generally lived near the health centers, and we assumed that caregivers traveled together with the patients.

We do not separately report results based on data for less than 10 respondents, but we do include the information in aggregate results. For example, we do not report time missed for post-colonoscopy visits because few respondents who attended one missed work. However, we do include this time in the total time. We follow the same logic for data reported on costs. So few respondents reported requiring child care that we excluded them from the total costs.

3. Results

Patients who received free colonoscopies are described in Table 1. Three-quarters were women, and on average, they were 58.9 years old (range = 52–81). Most were African Americans (69.3%) and fluent in English (72.7%). Seventy-three percent of respondents had at least a high school diploma or the equivalent. Thirty-eight percent of respondents were employed either full- or

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