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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.

Keywords

Colonoscopy;	Cancer	screening;	Patients and	caregivers	costs and	cost	analysis	

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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 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 had 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 innercity 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 had 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 part-time, and more than half (56.1%) were employed in the services industry (e.g., home health aide, firefighter, cook, maid, waitress, gardener/landscaper). Only 16.0% had health insurance (private, Medicare, or Medicaid).

Respondents were asked about the people who accompanied them to the various colonoscopy appointments. All respondents had someone accompany them to attend at least one appointment. Most often (72.0%) this person was a family member or spouse. Among caregivers, 29.3% were employed full-time and 14.7% were employed part-time. Many of those who were employed (36.8%) were in the services industry.

Not all employed patients missed work for various parts of the colonoscopy process, likely because they were able to schedule the colonoscopy to fit their work obligations. Of employed respondents, 43.9% had to miss work to attend a precolonoscopy visit. Nearly one-quarter (22.8%) had to miss work to prepare for the colonoscopy, and slightly more than

half (50.9%) had to miss work for the colonoscopy itself. On average, employed respondents who missed work missed 6.1–8.0 h for each of the various colonoscopy appointments. Employed respondents missed 6.1 h of work for a precolonoscopy visit and 6.9 h preparing for and 7.4 h attending the colonoscopy.

Table 2 displays the time needed and estimated cost of this lost time for patients undergoing colonoscopies and caregivers. Patients spent approximately 1.2 h at a precolonoscopy visit and 0.9 h traveling to it, which resulted in \$24.95 in lost time. Thirty-seven percent of patients had someone accompany them to the precolonoscopy visit, equaling \$11.73 in lost time across all caregivers. To prepare for a colonoscopy, patients spent 16.9 h, including reading the bowel preparation instructions. This equaled \$196.54 in lost time. Patients spent 0.8 h traveling to and from the endoscopy center and 3.7 h having the colonoscopy resulting in a mean patient value of lost time of \$51.97. Patients took 5.1 h to recover from the colonoscopy, translating into \$59.80 in lost time. Only 13.3% of respondents reported having a postcolonoscopy visit. Across all respondents, patients spent 0.1 h in travel and 0.1 h at the visit, and this translated into \$2.68 in lost time. In total, patients needed 28.8 h to undergo the colonoscopy screening, resulting in an indirect average cost of \$335.95, while it cost the caregiver \$79.03.

Fig. 1 compares how respondents traveled to the precolonoscopy and the colonoscopy visits. Most respondents traveled to the precolonoscopy and colonoscopy visits by car (69% and 89%, respectively). A small percentage of respondents paid to park at the doctor's office (9.3% and 10.7% for the precolonoscopy and colonoscopy visit, respectively). Three times as many respondents took public transportation or walked to the precolonoscopy appointment compared to the colonoscopy visit (31.3 versus 10.3%).

Table 3 shows travel and other costs for all colonoscopy visits. Across all patients, the travel costs were \$13.10. The cost for traveling to the precolonoscopy visit was \$5.54 and the travel cost to attend the colonoscopy was \$6.75. Few attended a postcolonoscopy visit and the cost to travel to it was \$0.81 when averaged across all patients. The average cost of the bowel preparation product was \$4.36.

4. Discussion

In this study, based on retrospective self-reports, patients spent, on average, 23.7 h preparing for, traveling for and having a colonoscopy, and an additional 5.1 h, on average, recovering from the colonoscopy. This translated into a total cost of \$335.95 for the patient in lost time and \$79.03 for the caregiver. In addition, an estimated \$17.46 was incurred in travel and other costs. Even when colonoscopy is provided free of charge to the patient, additional costs may be incurred which could be a significant barrier for low income individuals to receive CRC screening.

A few international studies have estimated the non-medical costs of screening colonoscopies but these estimates are not directly comparable to the present study that collected data on a low-income patients in the United States. Using patient questionnaires to collect nonmedical costs of both fecal occult blood test (FOBTs) and colonoscopies, researchers in Canada

found that the costs for both patients and caregivers averaged Can\$308 (2006 U.S. \$271) for colonoscopy and Can\$36 (2006 U.S. \$32) for FOBTs (Heitman et al., 2008). Examining the indirect cost of flexible sigmoidoscopies through the use of patient surveys in Great Britain, researchers found that indirect costs totaled approximately £23 (1999 U.S. \$14.20) (Frew et al., 1999). A study that was performed in the United States did not report costs but estimated that the time required to complete the screening colonoscopy process as approximately 21 h, (Jonas et al., 2007) which is similar to the time reported in this study.

Overall, the total cost of undergoing a "free" colonoscopy screening is substantial for a lowincome patient, especially when the average hourly wage estimate used in this analysis for the patient was \$11.68. This relatively high cost could explain the reason for the lower levels of compliance with screening recommendations among people with low education and generally low socioeconomic status (Centers for Disease Control and Prevention, 2013). Further, many service workers lack paid sick time, which may further impact the use of endoscopy tests (Peipins, Soman, Berkowitz, & White, 2012). The largest time cost was related to bowel preparation and undergoing the colonoscopy procedure; therefore, potentially, noninvasive fecal-based tests could result in lower burden in terms of time lost. Fecal tests, though, require much more frequent screening than colonoscopy and, therefore, may not effectively save much money over the long term. The need to repeat screening tests at regular intervals is also an important issue: if the need for multiple repeated screens is not met, especially for annual fecal tests, then there is a substantial reduction in the effectiveness of the test (Subramanian, Bobashev, & Morris, 2009; Subramanian, Bobashev, & Morris, 2010). In addition, colonoscopy may be an appropriate surveillance test for high-risk individuals (those with a family history of CRC or other risk factors) (U.S. Preventive Services Task Force, 2015). Colonoscopy is also required for diagnostic follow-up testing when fecal-based tests are positive; therefore, understanding approaches to improve completion of the screening process with colonoscopies is an important aspect of any CRC initiative that relies on fecal tests.

The role of financial incentives to increase patient compliance with colonoscopy screening recommendations is an understudied area of research. Pignone et al. (2014), using a discrete choice experiment, found that participants undergoing CRC screening preferred rewards or small copayments, compared to large copayments. The most recent review published by the Guide to Community Preventive Services found insufficient evidence to recommend patient incentives (Sabatino et al., 2012). Systematic evaluation of the role of incentives in screening colonoscopy use among the low-income population is needed. In addition, comparative evaluation of the role of fecal-based tests compared with that of colonoscopies is also essential to assess each screening test's ability to address the low screening rates among the low-income, underinsured, and uninsured populations.

The study has several limitations. First, the retrospective nature of the study could have resulted in recall bias related to the time allotted to specific screening procedures. Second, the estimates are based on a nonrandom sample of patients within one city, so these results may not be generalizable to other populations. In addition, we did not include a comparison group to assess differences in time and cost of undergoing colonoscopy. Third, these cost estimates are likely to be a conservative estimate of the overall cost incurred. For example,

costs for bowel preparation were low because we learned that a local store sold the product inexpensively and the health centers were able to provide free kits to some patients. Despite these limitations, the detailed breakout of the costs presented in this study offers program planners and policy makers a good approximation of the costs involved. This estimate can be tailored based on unique situations that may be present in the implementation of other colonoscopy screening programs.

5. Conclusions and lessons learned

The findings from this study offer insights into the economic barriers faced by low-income individuals when undergoing colonoscopy screening, even when the procedure itself is offered at no charge. Additional studies are required to understand the role of financial incentives and the most effective use of these incentives. The decision to undergo colonoscopy screening can be influenced by multiple interlinked factors, so financial incentives should be evaluated alongside other potential barriers. Financial incentives should be included in future assessments of health promotion interventions, as colonoscopy screening requires a substantial time commitment and the cost of lost time is significant, especially for the low-income population.

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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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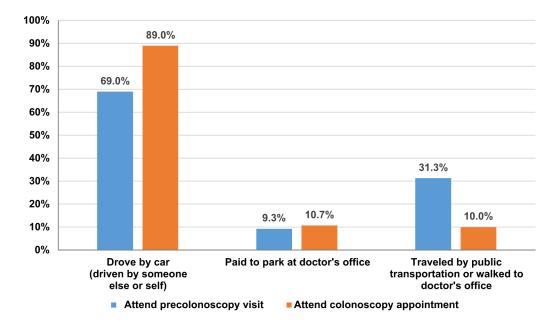


Fig. 1.
How Respondents Traveled to Doctors' Appointments.

Note: One person did not report mode of transportation for colonoscopy appointment.

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Table 1

Demographics Education, and Employment Status of Patients Undergoing Colonoscopy.

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Variables	N	%
Age (years)		
52–59	84	56.0
60+	66	44.0
Female	112	74.7
Race		
Black or African American	104	69.3
Asian	28	18.7
Other	18	12.0
Fluent in English	109	72.7
Highest grade of school or college finished a		
Less than high school	41	27.3
High school or GED	53	35.3
More than high school	56	37.3
Employment status (patient)		
Working full-time	35	23.3
Working part-time	22	14.7
Not working (includes retired, staying at home to work, keeping house)	93	62.0
Current work status—position (patient)		
Services	32	56.1
Other (e.g. transportation, production and maintenance)	25	43.9
Health insurance		
No insurance	126	84.0
Medicaid/medical coupons/CHIP	14	9.3
Other (Medicare, private coverage)	10	6.7
Relationship of person who accompanied you		
Spouse	26	17.3
Friend	42	28.0
Other family member	82	54.7
Employment status (caregiver)		
Working full-time	44	29.3
Working part-time	22	14.7
Not working (includes retired, staying at home to work, keeping house, don't know)	84	56.0
Current work status—position (caregiver)		
Services	25	36.8
Professional	12	17.6
Other (e.g. transportation, production and maintenance)	31	45.7

^aValues do not total 100% because of rounding.

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Table 2

Mean Number of Hours Needed for a Colonoscopy and Estimated Value of Time Spent.

Variables	N In	Incurred by Patients			Incurred by Caregiver ^a
	ĕZ	Mean hours per patient (across all patients)	Mean cost per patient (across all patients)	% of patients reporting activity	Mean cost per patient (across all patients)
Attend precolonoscopy office visit					
Visited a nurse or doctor before the colonoscopy	150 n/a	а	n/a	n/a	n/a
Average hours spent at doctor's office	150 1.2	2	\$14.13	36.7	\$6.64
Average hours spent traveling to the doctor's office	150 0.9	6	\$10.82	36.7	\$5.09
Subtotal	2.1	1	\$24.95		\$11.73
Prepare for colonoscopy					
Average hours spent reading bowel preparation instructions $^{\it b}$	150 0.3	33	\$3.12	n/a	n/a
Average hours spent preparing for colonoscopy	150 16	16.6	\$193.42	n/a	n/a
Subtotal	16	16.9	\$196.54		n/a
Attend colonoscopy visit					
Average hours spent getting to and from the endoscopy center	150 0.8	8	\$9.34	100	\$11.98
Average hours spent at endoscopy center	150 3.7	7	\$42.63	100	\$54.64
Average hours it took to recover from the colonoscopy	150 5.1	1	\$59.80	n/a	n/a
Subtotal	9.6	9	\$111.78		\$66.62
Attend postcolonoscopy visit					
Average hours spent getting to and from post-colonoscopy visit	20 0.1	1	\$1.25	2.7	\$0.32
Average hours spent at post-colonoscopy visit	20 0.1	1	\$1.43	2.7	\$0.37
Subtotal	0.2	2	\$2.68		20.69°C
Total average cost of lost time			\$335.95		\$79.03
Total average time in hours		28.8 h per patient;	28.8 h per patient; 5.3 h for caregiver		

Weighted average wage for respondent = \$11.68.

Weighted average wage for accompanying person (caregiver) = \$14.97.

 $^{^{}a}$ Amount of time spent per visit was assumed to be the same for both patient and person accompanying patient.

bOne person indicated they did not remember how many minutes it took to read the instructions, so we imputed the average.

 $^{^{\}mathcal{C}}$ Subtotal is based on small sample.

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Table 3Travel and Other Costs for Colonoscopy Office Visits.

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	IV	% of patients reporting activity	Mean cost per patient reporting activity	Mean cost per patient (across all patients)
Travel Cost				
Attend precolonoscopy office visit				
Cost to travel to doctor's office by $car^{a,b}$	103	68.7	\$23.30	\$4.17
Cost to travel to doctor's office by public transportation $^{\mathcal{C}}$	41	27.3	\$5.00	\$1.37
Subtotal			\$28.30	\$5.54
Attend colonoscopy visit				
Cost to travel to doctor's office by $car^{a,b}$	134	89.3	\$26.30	\$6.28
Cost to travel to doctor's office by public transportation $^{\mathcal{C}}$	14	9.3	\$5.00	\$0.47
Subtotal			\$31.30	\$6.75
Attend postcolonoscopy visit	13	8.7	\$25.35	\$0.81
Costs of travel to attend postcolonoscopy $visit^{b,d}$				
Subtotal			\$25.35	\$0.81
Total travel cost				\$13.10
Cost of bowel preparation product	61	40.7	\$10.71	\$4.36
Total				\$17.46

 $^{^{}a}$ Includes cost of payment to be driven to doctor's office, cost to park at doctor's office and mileage costs.

b Assumed 10-mile distance to endoscopy center (round trip = 20 miles). Used 2013 IRS mileage for medical purpose of 23 cents. Excluded respondents who reported payment for transportation or took public transportation.

^CFor transportation cost, the percentage of patients will not sum to 100% as some individuals walked and one person did not report mode of transportation for colonoscopy visit.

^dOnly 20 respondents attended a postcolonoscopy visit. Due to small sample size, the following categories comprise the total but could not be reported separately: cost of payment to be driven to doctor's office; cost to park at colonoscopy appointment; cost to travel to doctor's office by bus, train, or taxi; mileage costs for postcolonoscopy visit.