Family Medicine and Community Health

Patients' experiences with 'sludge' (administrative burden) in the cancer screening process and its relationship with screening completion, experience and health system distrust

Michelle S Rockwell ,[1,2] Brianna Chang,[3] Vivian Zagarese,[4] Jamie K Turner,[2,5] Ally Southworth,[2] YingXing Wu,[6] Paul Yeaton,[7] Li Li,[8] Jeffrey S Stein,[9] Sarah H Parker,[4] John W Epling[1,2]

To cite: Rockwell MS, Chang B, Zagarese V, *et al*. Patients' experiences with 'sludge' (administrative burden) in the cancer screening process and its relationship with screening completion, experience and health system distrust. *Fam Med Com Health* 2024;**12**:e002933. doi:10.1136/fmch-2024-002933

► Additional supplemental material is published online only. To view, please visit the journal online (https://doi.org/10.1136/fmch-2024-002933).

For numbered affiliations see end of article.

Correspondence to
Dr Michelle S Rockwell; mrockwell@carilionclinic.org

ABSTRACT

Objective 'Sludge' refers to administrative burdens or frictions that preclude people from getting what they want or need (eg, duplicative forms, complicated instructions, long waiting times). This mixed methods study evaluated patients' perceptions of sludge in the colorectal cancer (CRC) screening process and some impacts of this sludge.

Design We employed an exploratory sequential mixed methods study design that comprised patient interviews and a patient survey. The interviews informed final survey revisions and captured contextual data about patients' experiences with sludge. Interview transcripts were inductively and deductively analysed to identify overarching themes. The survey quantified sludge, delayed or forgone screenings, screening experience (Net Promoter Score) and health system distrust (Health System Distrust Scale). We used χ^2 or t-tests for univariable comparisons and logistic or linear regressions to evaluate the association between cumulative sludge score and delayed or forgone screenings, screening experience and health system distrust. Results were integrated for interpretation.

Setting Southeastern United States.

Participants Patients who were 45–75 years of age, at average risk for CRC and had either completed or been referred for CRC screening (colonoscopy or stool-based test) within the previous 12 months.

Results 22 interview participants and 255 survey participants completed the study. 38 (15%) survey participants rated their screening experience as poor (Net Promoter Score=0–7 out of 10). The mean (SD) Health System Distrust Scale score was 22.4 (6.3) out of 45 possible points (higher score=greater distrust). Perceptions of sludge in the CRC screening process varied, with long waiting times and burdensome communication being the most common sources (58% and 35% of participants, respectively). Sludge was positively associated with delayed or forgone screenings (OR=1.42, 95% CI 1.28, 1.57, p<0.001), poor screening experience (OR=1.15, 95% CI 1.04, 1.28, p=0.009) and health system distrust (β=0.47, p<0.001). Qualitative findings add descriptive detail about sludge encountered, context to impacts experienced, and illustrate the heavy emotional impact of sludge: '*it just isn't worth it*'.

Conclusion Efforts to reduce sludge in the CRC screening process may improve timely completion of CRC screening, enhance patient experience and restore trust in the health system.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Administrative burden is ubiquitous in healthcare. The administrative burden that precludes or delays healthcare delivery can be described as 'sludge'. Although there are numerous calls to reduce the sludge that clinicians and patients experience in healthcare processes, patients' experiences with healthcare sludge have not been well described.

WHAT THIS STUDY ADDS

⇒ This study illuminates patients' self-reported experience with sludge encountered in the colorectal cancer (CRC) screening process in the Southeastern United States. Sludge was associated with delayed or forgone screenings, poor experience and health system distrust. Participants with socioeconomic disadvantage experienced disproportionate sludge.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Study findings highlight numerous opportunities to improve CRC screening rates and enhance patient experience through clinical, operational and policy-level efforts to reduce sludge and streamline the care transitions associated with CRC screening.

INTRODUCTION

With more than 2 million new cases diagnosed annually, colorectal cancer (CRC) is a leading cause of cancer-related deaths worldwide.[1] Screening can play an important role in the prevention and early detection of CRC, but a significant number of individuals fail to

receive timely screening. For example, in the USA, over 55 million individuals are eligible for CRC screening but have not received it.[2] Further efforts are needed to identify approaches for improving access to and completion of CRC screening.

Previous research suggests that 'sludge' is an underexplored barrier to the completion of CRC screening.[3 4] A behavioural economics term popularised by Harvard Law professor and author, Cass Sunstein, sludge describes administrative burdens or frictions that prevent people from achieving their goals.[5] Examples of sludge include redundant paperwork, complicated or inconsistent instructions, cumbersome communication and long waiting times.[6] As a complex, multistep pathway involving several screening test options (eg, colonoscopy, stool-based tests, flexible sigmoidoscopy), variable testing intervals and multiple care transitions (eg, primary care to gastroenterology to screening facility), the CRC screening process may be particularly prone to sludge. Although the impact of sludge on patients is not well recognised in the literature, there is evidence that patients may delay or forgo recommended care as a result of sludge, especially when they are in poor health.[4 7 8] In addition, sludge can contribute to psychological distress, confusion and anger and there is some evidence that sludge decreases trust.[9 10] Importantly, sludge may disproportionately impact disadvantaged patients, which can widen health and healthcare disparities.[10–12]

There are multiple calls to reduce sludge in healthcare,[13–19] including the National Health Service *Bureaucracy Busting Concordat*[20] and the American Medical Association's campaign for *Getting Rid of Stupid Stuff*.[21] Improved understanding of patients' experiences with sludge is needed to respond to such calls through clinical, operational and policy-level efforts to improve the CRC screening process and enhance screening rates. Thus, the purpose of this mixed methods study was to evaluate patients' experiences with sludge in the CRC screening process and to explore some impacts of this sludge. We hypothesised that sludge in the CRC screening process is: (a) common; (b) related to delayed or forgone screenings, poor screening experience and health system distrust; and (c) differentially experienced by patients living in rural areas and with socioeconomic disadvantage.

METHODS

Using an exploratory sequential mixed methods study design,[22] we conducted a qualitative interview of patients who had recently engaged in the CRC screening process, followed by a quantitative survey of a second group of patients who had recently engaged in the CRC process. The semistructured interviews informed refinements to the patient survey and offered contextual insight into patients' experiences with sludge in the CRC screening process. The survey quantified patient-reported sludge in the CRC screening process and evaluated the relationship between this sludge and delayed or forgone screenings, screening experience and health system distrust.

Informed consent was provided by participants before beginning the study. The Strengthening the Reporting of Observational Studies in Epidemiology for cross-sectional studies,[23] the Consolidated Criteria for Reporting Qualitative Research[24] and Advancing the Reporting of Mixed Methods Studies[22] checklists guided our research and the development of this report. The following abbreviations are used in the results: primary care provider (PCP), faecal immunochemical test (FIT), FIT-DNA test (Cologuard).

Participants and setting

This study was conducted in southwest and south-central Virginia where the CRC screening rate is the lowest and CRC incidence is the highest in the state.[25 26] Interview and survey participants were mutually exclusive groups of patients who were 45–75 years of age, had either completed or been referred for CRC screening (colonoscopy or stool-based test) at a health system, centre or practice in southwest or south-central Virginia within the previous 12 months, and had no history of gastrointestinal cancer or inflammatory bowel disease (at any point) or gastrointestinal pain or rectal bleeding within the past 12 months. Participants were compensated via gift cards.

Procedures

Study procedures are shown in figure 1.

Interviews

Prospective participants, identified via health system records or recruited via targeted regional social media posts, were invited to screen for eligibility to participate in a semistructured interview focused on their experience with CRC screening by completing a brief online screening

DATA COLLECTION 1	ANALYSIS 1	DATA COLLECTION 2	ANALYSIS 2	INTEGRATION	PRESENTATION
Interview (n=22)	Study team review for final survey modifications.		Reflective thematic analysis using inductive and deductive coding by 4 independent reviewers.	Review of interview and survey results by expert panel. Research team integration sessions.	Narrative weaving approach, including joint display of sludge type results.
		Survey (n=255)	-Descriptive statistics -Univariable comparisons -Regression analysis to evaluate the relationship between cumulative sludge score and delayed/foregone screenings, experience, and health system distrust.		

Figure 1 Overview of exploratory sequential mixed methods study design.

instrument administered via REDCap.[27] Eligible participants were enrolled, consented and engaged in one approximately 60 min interview session with a researcher (BC) via video chat or in person in a private office space. The interview guide is included in online supplemental file 1. Additional information for the qualitative procedures is included in online supplemental file 2.

During Part 1 of the interview, participants completed a pilot version of the survey, pausing at designated points to provide feedback on the structure, format and clarity of survey questions and instructions. Participants then responded to the researcher's open-ended questions during Part 2 of the interview, beginning with a request to share a detailed account of their recent experience with the CRC screening process and followed by prompts to elicit further details about sludge in the screening process, and if applicable, their response to any sludge experienced. The researcher kept field notes during both parts of the interviews and continued interviews until thematic saturation was achieved. Interviews were audio recorded and later transcribed for analysis. Transcript feedback was not elicited from participants.

Survey

Using the same eligibility criteria described in the previous section, patients were invited to participate in a survey about their experience with the CRC screening process (online supplemental file 3). Developed by the research team and iteratively refined through collaborative work sessions, community engagement studios,[28] internal pilot testing and participant feedback during interview Part 1, the survey consisted of original and previously validated questions focused on sludge, screening experience and health system distrust. A summary of the survey development and evaluation process is included in online supplemental file 4.

To evaluate sludge, participants were asked about their experience with administrative burdens that felt excessive or unnecessary during their CRC screening process (defined as beginning when a healthcare provider recommended screening and ending when the provider and the patient both receive results). Participants who had not completed the screening were asked to respond based on whatever portion of the process they had completed. Informed by previous work,[3 7 8] we specifically asked participants to quantify (on a 0–100 sliding scale) the amount of paperwork, communication, technology and waiting that felt excessive or unnecessary during the CRC screening process, with several examples provided for each (online supplemental file 3). Two categories were assigned for waiting based on participant feedback offered throughout the survey refinement process (including interview Part 1). 'Waiting–passive' represented a delay or period of time during which the patient was waiting for a step in the CRC screening process to occur, but during which their time was not occupied (eg, waiting to be called to schedule a colonoscopy appointment, waiting for the appointment to occur, waiting to receive results), whereas 'waiting–active' represented the time, typically on-site in a healthcare facility, when patients were waiting for something to occur and during which they were not available to do something else (eg, in a waiting room). We calculated a cumulative sludge score by summing the sliding scale ratings for each sludge type for a potential score of 500. Participants were also asked in which phase(s) of the screening process (referral, scheduling, preparing, the test itself, acquiring results) they experienced each type of sludge.

To evaluate the impact of sludge on patients, we assessed three outcomes: delayed or forgone screenings, screening experience and health system distrust. Informed by the work of Kyle and Frakt,[8] we assessed delayed or forgone screenings via two questions: *Was your colorectal cancer screening test delayed due to excessive or unnecessary administrative burden?* and *Did you skip your colorectal cancer screening test due to excessive or unnecessary administrative burden?* We used the single-item Net Promoter Score (NPS)[29] (*How likely would you be to recommend this screening process to a close friend or family member?*), with 0 indicating *not at all likely* and 10 indicating *extremely likely* to assess ratings of screening experience and the Healthcare System Distrust Scale (HSDS)[30] to assess overall health system distrust.

General demographics and CRC screening characteristics (eg, type of screening test) were also collected. We used the US Department of Agriculture Rural-Urban Commuting Area codes to determine rurality.[31] Based on a priori power analysis showing that a sample size of 234 participants was needed to show a moderate effect size at the 0.05 level, we aimed to recruit 250 participants in anticipation of incomplete surveys.

Data analysis

Interview analysis

For interview Part 1, one researcher (MR) listened to audio recordings of interviews, summarising potential survey modifications that emerged from participants' feedback. This summary was combined with the interviewer's field notes and reviewed with the senior author (JWE) to inform minor survey edits. For interview Part 2, interviews were auto transcribed using Microsoft Teams, with two researchers (JT and MR) manually verifying accuracy. Transcripts were uploaded to NVivo (QSR International, Melbourne, Australia) for analysis.

The qualitative analysis team used reflexive thematic analysis to identify and interpret themes that emerged from the data.[32] To obtain a codebook that included different perspectives, four researchers analysed transcripts, with VZ and AS using an inductive approach (emerging themes) and JT and EO using a deductive approach informed by themes identified in community engagement studios and our prior work.[3] Through an iterative, multiphase process, the codebooks were consolidated and refined to focus on participants' experiences with sludge in the CRC screening process and their response to this sludge. We used Cohen's kappa to assess coder agreement, with the average agreement among

Table 1 Demographic and screening characteristics of participants

	Interview (n=22)	Survey (n=255)
Age (years)		
45–54	8 (36.4%)	98 (38.4%)
55–64	7 (31.8%)	74 (29.1%)
65–74	7 (31.8%)	83 (32.5%)
Gender		
Male	6 (27.3%)	88 (34.5%)
Female	14 (63.6.%)	165 (64.7%)
Other or unknown	2 (9.0%)	2 (0.8%)
Race		
Asian	0 (0.0%)	5 (2.0%)
Black or African American	0 (0.0%)	6 (2.4%)
White	21 (95.5%)	235 (92.0%)
More than one race	1 (4.5%)	4 (1.6%)
Other	0 (0.0%)	5 (2.0%)
Ethnicity		
Hispanic/Latino	0 (0.0%)	4 (1.6 %)
Non-Hispanic/Latino	22 (100%)	237 (92.9%)
Unknown	0 (0.0%)	14 (5.5%)
Rurality		
Rural	6 (27.4%)	65 (25.5%)
Non-rural	16 (72.6%)	190 (74.5%)
Payer		
Commercial	12 (54.5%)	126 (49.4%)
Medicare	5 (22.7%)	69 (27.1%)
Medicaid	3 (13.8%)	40 (15.7%)
Dual Medicare-Medicaid	1 (4.5%)	17 (6.7%)
Other	1 (4.5%)	3 (1.2%)
Employment		
Employed full time	6 (27.4%)	101 (39.6%)
Employed part-time	3 (13.6%)	28 (11.0%)
Not working, not retired	3 (13.6%)	16 (6.3%)
Retired	8 (36.4%)	93 (36.5%)
Full-time student	0 (0.0%)	1 (0.3%)
Other	2 (9.0%)	16 (6.3%)
Screening completion status		
Referred	4 (18.2%)	61 (23.9%)
Complete	18 (82.8%)	194 (76.1%)
Screening type		
Colonoscopy	16 (72.6%)	176 (69.4%)
Stool-based test	6 (27.4%)	78 (30.6%)

all four coders being 0.69 (moderate agreement).[33] The final output was a table of interview themes and exemplary quotations in online supplemental file 5.

Survey analysis

Continuous variables were summarised using either the mean with SD or the median with IQR, while categorical variables were presented as percentages. Strata for cumulative sludge scores (≤25 and >25) and NPS (0–7 and 8–10) were determined via visual inspection of data distributions. We conducted univariable comparisons using t-tests (or Wilcoxon two-sample tests) and analysis of variance (or Kruskal-Wallis tests) for continuous variables and χ^2 tests (or Fisher's exact tests) for categorical variables. The association between the cumulative sludge score and primary outcome variables (delayed or forgone screenings, screening experience, distrust) was evaluated using linear and logistic regressions with the following candidate variables included in the regressions: cumulative sludge score, age group, gender, race, rurality, insurer, screening status and screening type. Ethnicity was not included in the analysis due to the limited number of Hispanic/Latino participants. To assess the contribution of each sludge type, we ran additional exploratory regressions with individual sludge-type subscores retained without variable selection. Statistical analyses were performed using R V.4.2 (https://cran.r-project.org/).

Integrated data analysis

To complement the research team's interpretation of interview and survey results, we invited 16 professionals with expertise in CRC screening, behavioural economics, health equity, healthcare operations, health policy and/or patient advocacy to serve on an external expert panel. Panellists independently reviewed summaries of interview themes and survey results and responded to a structured online survey (online supplemental file 6). Research team members were presented with interview and survey results and expert panel responses. The senior author (JWE) guided collaborative discussions to identify areas of convergence, complementarity or dissonance in the data and to come to consensus on key findings.

RESULTS

A total of 22 participants (mean (SD) age: 55.4 (9.2) years, 64% women) engaged in interviews, while 262 participants completed surveys (67% response rate) (table 1). Seven survey responses were omitted since they were less than 80% complete, leaving a final sample of 255 (mean (SD) age: 58.2 (8.4) years, 65% women).[34] Demographic characteristics of the interview and survey cohorts are representative of the southwest and south-central Virginia regions. Below, we weave survey results with key themes and exemplary quotes from open-ended survey responses and the thematic analysis of interviews.[24]

Sludge in the CRC screening process

Most survey participants (n=178, 70%) experienced excessive or unnecessary administrative burdens or frictions during the CRC screening process (sludge score >25). Cumulative sludge scores ranged from 0 to 355 out

Table 2 Patient-reported sludge experienced in the colorectal cancer screening process

Sludge types	% of survey participants experiencing sludge type (n=255)	Sample interview participant description
Waiting–passive	52	'There are no available dates for 1 or 2 years. How can that even be?'
Waiting–active	47	'It is 3 hours round trip for me to go there so it is a half day off work just for the PCP appointment and then again to go see the [pre-operative] nurse and then again to pick up the [colonoscopy prep] and then like a day and a half for the colonoscopy. You've got to be really invested in it to spend your vacation time on all that.'
Communication	35	'I heard nothing for a year. So, I called and found out they kicked me off the referral list after one year without even telling me so now I had to start again.' '…sent me like 4 different instructions and they all said to do something different.'
Paperwork	32	'…didn't know how to answer most of the questions on this really long form that we had to send off with the test. They were asking the same thing over and over again.'
Technology	26	'That scheduling website they have doesn't even work. It just spins and spins and there is no number to call and ask questions. There is no one. It's like they don't want you to get the colonoscopy.'

of 500 possible points, with mean (SD) of 95.1 (89.2) and median (IQR) of 68 (16, 157). Waiting–passive was the most common type of sludge experienced, followed by waiting–active, communication, paperwork and technology (table 2).

Cumulative sludge score varied by screening completion status (completed—median (IQR): 51 (12, 129) vs not completed—154 (70, 215), p<0.001); interview participants described feeling relieved or '*better about all the hassle*' after the test was over. Sludge was reported in all phases of the CRC screening process but varied by screening phase and screening type (figure 2). Survey participants who had completed screening reported sludge in 0 (43%), 1 (24%), 2 (18%), 3 (11%) or ≥4 (4%) phases, with scheduling the screening test as the most common (41%). Interview participants described missed calls, voicemails and '*a never-ending game of phone tag*' during scheduling.

Participants who had stool-based tests described confusion, ranging from '*not clear*' to '*utter chaos*' around multiple phases of the process. They found that instructions were inconsistent or incomplete, difficult to understand and that there were forms they needed but did not have. Some described challenges with scheduling a time to pick up their test kit. Others reported that they never received results and, in some cases, that their ordering clinician did not receive results either.

> You have to go to some other place to pick up the special testing kit or else your insurance won't cover it. I don't have time to mess with going to yet another place.
>
> …I didn't understand what to do so I just threw it in the trash.
>
> I did not understand the directions for Cologuard. It says it is easy but there were like 10 steps, and I had no clue what to do.
>
> They literally lost my poop card in the mail. WTF?

Cumulative sludge score was significantly higher for participants with Medicaid or dual Medicare-Medicaid (median (IQR): 79 (36, 169)) versus other payers (median (IQR): 60 (23, 126)) (p=0.048), but did not differ by other demographics (online supplemental file 7). Reports of sludge related to financial processes were common.

> …can't figure out how to use my insurance website to know if this will be covered without my daughter's help.
>
> I keep worrying about all those forms you have to turn in because if I do it wrong, they are going to mess up and charge me—that always happens—and I don't have time to deal with it and I can't pay for it.
>
> …getting all the billing stuff straightened out every single time…well, it just isn't worth it.

Some participants perceived inequality in the waiting time for colonoscopy, stating that '*it's all about who you know*' and '*whether or not your doctor is part of their system*' that determines waiting time. Others perceived profit-motivated drivers of sludge in the screening process.

> They take anyone with the best insurance first, so they make more money.
>
> …no way that someone poor like me is going to make it to the top of the wait list no matter what my risk is because they say that Medicaid and Medicare don't pay them good.

Figure 2 Types of sludge reported in each phase of the colorectal cancer screening process (colonoscopy and stool-based tests). The cumulative sludge score was higher for colonoscopy (median 76 (IQR 25,166)) than stool-based tests (median 48 (IQR 9, 150)) (p<0.05). IT, information technology.

There were a few examples of participants misunderstanding the concept of administrative burden or sludge. Some misattributed the high cost of care, having to complete the colonoscopy prep, and concern about anaesthesia to sludge.

Impact of sludge in the CRC screening process on patients

Delayed or forgone screenings, poor experience and health system distrust

81 (37%) of survey participants indicated that their CRC screening test was delayed or forgone due to excessive or unnecessary paperwork, communication, technology or waiting. 38 (15%) survey participants rated their experience as poor (NPS of 0–7 out of 10). The mean (SD) for HSDS was 22.4 (6.3) out of 45 possible points (higher score=greater distrust). Variation in outcomes by demographic and screening characteristics is included in online supplemental file 7.

Compared with survey participants who reported sludge in the CRC screening process, those who reported no sludge or very minimal sludge (cumulative sludge score ≤25) had a lower proportion of delayed or forgone screenings, fewer poor experience ratings and lower distrust scores (figure 3). In our regression analysis using variable selection (table 3), there was a positive relationship between cumulative sludge score and delayed or forgone screening, poor screening experience and health system distrust. In a separate regression run without variable selection to explore prediction of the outcomes with each type of sludge, there was a positive relationship between cumulative sludge score and delayed or forgone screening, poor screening experience and health system distrust (table 4). Sludge in technology and both waiting variables was associated with delayed or forgone screenings, sludge in communication was associated with poor screening experience and sludge in communication and waiting–passive was associated with health system distrust.

> …after a while, you just say forget it. It's not worth it.
>
> I'm not really likely to recommend this process… it's hard…especially when you work full time…

Participants expressed a general expectation that accessing healthcare is associated with '*jumping through multiple hoops*', '*scheduling really far out*', '*being your own advocate*' and resigning to '*the broken system*'.

Some participants described factors that mitigated the impact of sludge. For example, family history of CRC, social support and previous experience with CRC screening helped participants persist through sludge.

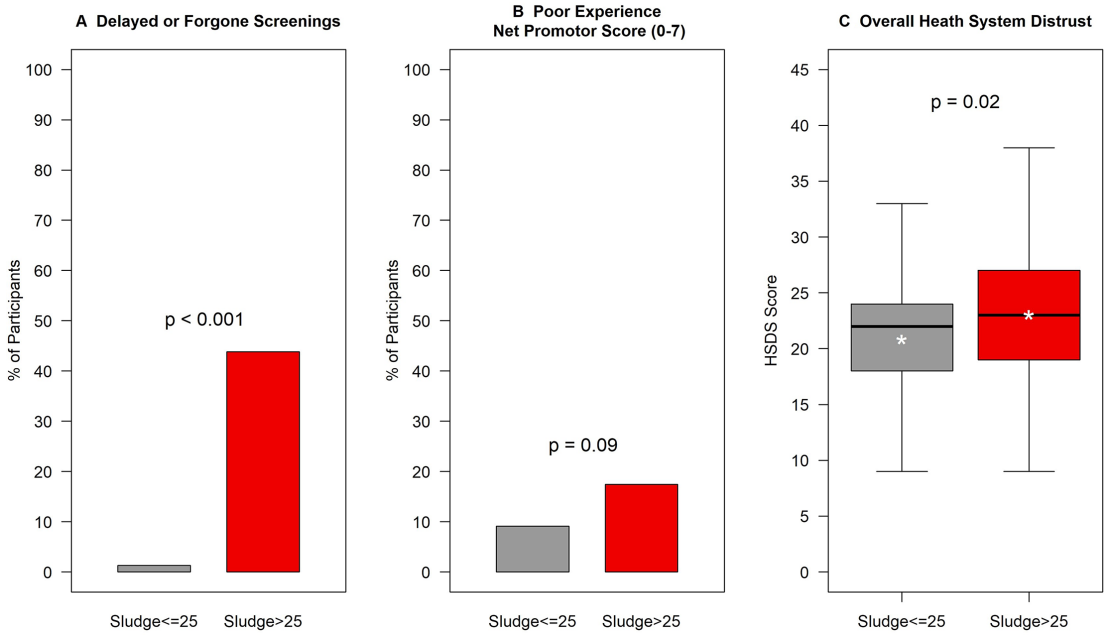

Figure 3 Delayed or forgone screenings (A), poor screening experience (B) and health system distrust (C) in patients who experience no or very minimal sludge versus sludge. Cumulative sludge score ≤25 (n=77), cumulative sludge score >25 (n=178). Overall health system distrust: Healthcare System Distrust Scale (HSDS); the vertical axis shows the maximum possible score. *Mean.

Relationship with a PCP also facilitated the process: '*if Dr. [name omitted] wants me to do it, I'm going to do it no matter what*'. In contrast, perceptions of personal risk, mistrust in the health system, previous negative experiences with healthcare and unfamiliarity with the screening process exacerbated the impacts of sludge.

DISCUSSION

Sludge describes the administrative burdens or bureaucratic 'red tape' that patients may face in the process of acquiring healthcare.[6] Understanding patients' experiences with sludge is crucial to responding to calls for reducing sludge and its harmful sequelae. In this mixed methods study, we found that most participants experienced some degree of sludge in the CRC screening process, with socioeconomically disadvantaged patients experiencing greater sludge. Those who experienced more sludge were more likely to delay or forgo screening, describe their screening experience as poor and report greater distrust in the health system. Given that delaying or forgoing screening increases CRC risk, efforts to reduce sludge may improve CRC screening rates and reduce the morbidity and mortality associated with CRC. Additionally, patient experience is an important component of healthcare quality,[35] and the eroding distrust in the health system is a widespread concern.[36 37] As such, reducing the sludge associated with the CRC screening process represents an

Table 3 The relationship between sludge score and delayed or forgone screening, screening experience and health system distrust

	Delayed or forgone screening		Poor screening experience (NPS 0–7)		Health system distrust	
Term	**OR (95% CI)**	**P value**	**OR (95% CI)**	**P value**	**β**	**P value**
Cumulative sludge score (per 25 points)	1.42 (1.28, 1.57)	<0.001	1.15 (1.04, 1.28)	0.009	0.47	<0.001
Screening status (complete vs referred)	0.38 (0.18, 0.77)	0.007	0.16 (0.07, 0.36)	<0.001	−2.07	0.022
Screening type (stool-based test vs colonoscopy)	–		2.74 (1.23, 6.13)	0.014	2.95	<0.001
Age (years) (65–75 vs 45–64)	–		–		−1.57	0.045

Results of logistic and linear regressions (with variable selection). HSDS (0–45; higher values indicate more distrust).
HSDS, Health System Distrust Scale; NPS, Net Promoter Score (0–7 (poor experience) out of 10).

Table 4 The relationship between individual sludge type and delayed or forgone screening, screening experience and health system distrust

	Delayed or forgone screening		Poor screening experience (NPS 0–7)		Health system distrust	
Term	OR (95% CI)	P value	OR (95% CI)	P value	β	P value
Paperwork (per 5 points)	0.93 (0.84, 1.04)	0.227	1.02 (0.92, 1.12)	0.748	0.13	0.227
Communication (per 5 points)	1.08 (0.97, 1.21)	0.146	1.17 (1.06, 1.28)	0.001	0.32	0.005
Technology (per 5 points)	0.89 (0.80, 1.00)	0.046	0.93 (0.84, 1.04)	0.184	−0.18	0.143
Waiting time–passive (per 5 points)	1.24 (1.15, 1.34)	<0.001	1.01 (0.94, 1.09)	0.744	0.18	0.037
Waiting time–active (per 5 points)	1.17 (1.08, 1.28)	<0.001	1.06 (0.95, 1.34)	0.160	0.02	0.861

Results of exploratory logistic and linear regressions (retaining all sludge types in the models). Health System Distrust Scale (0–45; higher values indicate more distrust).
NPS, Net Promoter Score (0–7 (poor experience) out of 10).

opportunity to enhance healthcare quality and take important steps towards restoring trust in the health system.

Our findings align with others' who have shown that individuals with socioeconomic disadvantage experience more administrative burden and greater negative impacts associated with this burden.[12 38–40] The concept of scarcity has been related to the experience of sludge.[41] Patients with limited resources (eg, finances, time, understanding) and overloaded with stressors may have less capacity to persist through sludge. Thus, reducing sludge may play an important role in reducing socioeconomic disparities in CRC screening and outcomes.

The scale-based outcomes in this study require some additional interpretation. The effect sizes observed for experience and distrust were generally small to moderate, but the qualitative data illustrate the depth of feeling associated with the outcomes. We chose a cut-off for the NPS (experience) that is felt to represent true dissatisfaction, rather than passivity, so even small magnitude findings of a poor experience in this study are meaningful.[29] We also consider any elevation in patients' distrust of the health system to be important, even if incremental. In addition, we noted a relationship between completion of screening and improved experience and distrust scores, which may be attributable to a form of recall or recency bias affecting respondents' answers. Since most CRC screening results are reassuring (negative findings), respondents who have completed screening will have had a 'good' final outcome and remember the experience as overall less traumatic. Further work in this area could ascertain screening results as additional information to aid analysis.

Subsequent efforts to uncover patients' experiences with sludge encountered in cancer screening processes and to reduce this sludge may call on existing frameworks[11 42] and sludge reduction efforts in non-healthcare fields[5 43 44] to focus on the following:

- Characterising additional impacts of sludge beyond delayed or forgone screenings, poor experience and distrust.
- Evaluating the intersection between sludge and other well-recognised barriers to cancer screening (eg, low perception of risk, fear, embarrassment).[45–47]
- Exploring sludge tolerance (ie, what makes some people resilient throughout sludge-heavy processes while others are more vulnerable?). Our qualitative results suggest several factors that mitigated or intensified sludge.
- Refocusing resources dedicated to improving the rate of delivery of preventive services to reducing health system and insurance-related sludge.
- Streamlining the coordination of care between primary care and others involved in the cancer screening process.
- Tailoring interventions to reduce sludge based on the associations identified in this study. For example, to enhance the patient experience, focusing on innovative communication efforts can keep patients engaged in the screening process as well as minimising perception of inequity or favouritism.
- Evaluating messaging and communication methods preferred by patients when waiting times (passive or active) are inevitable.
- Evaluating the impact and cost-effectiveness of patient navigator programmes to improve screening rates versus policy and process efforts to reduce sludge.[48 49]
- Incorporating quality metrics and incentives that promote administrative simplification and sludge reduction.
- In the USA, most public and private insurers are required to cover the costs of clinical preventive services graded A or B by the US Preventive Services Task Force, with zero associated out-of-pocket cost to patients, as described in Section 2713 of the

Affordable Care Act.[50] However, administration of this requirement is nuanced, can be sludge-laden, may require interaction with insurance companies and sometimes results in patient charges. Based on the burden of healthcare costs to many Americans and the concerns expressed by participants in the present study, assuring that patients are not responsible for out-of-pocket charges for cancer screenings, that there are no additional fees, that insurance-related paperwork and correspondence are minimised and simplified and that the number of uninsured patients is reduced is essential to improving CRC screening adherence, experience and outcomes.

Limitations

Our study had some limitations. Although our participant cohorts were representative of the region and included participants affiliated with multiple health systems, centres and providers, the lack of diversity of our cohort (eg, racial, ethnic, language) and single region studied may limit the generalisability of results. Additionally, we report on the impact of sludge on only three outcome variables based on previous work by our team and others,[3 7 12] although we recognise that sludge likely impacts patients in numerous and potentially overlapping ways. Finally, the NPS, used to evaluate participants' experience with the CRC screening process, is limited to a single question assessment that may not capture the complexity of decision-making around CRC screening.

CONCLUSION

There are numerous national calls to reduce the harmful administrative burden—sludge—encountered by patients as they seek recommended healthcare services. In this patient-focused, mixed methods study, sludge in the CRC screening process was positively associated with delayed or forgone screenings, poor screening experience and health system distrust. Participants with socioeconomic disadvantage experienced more sludge and greater impacts of sludge compared with those without socioeconomic disadvantage. Clinical, operational and policy-level efforts to reduce sludge may improve CRC screening rates, reduce disparities, enhance experience and reduce health system distrust.

Author affiliations
[1]Department of Family and Community Medicine, Virginia Tech Carilion School of Medicine, Roanoke, Virginia, USA
[2]Department of Family and Community Medicine, Carilion Clinic, Roanoke, Virginia, USA
[3]Virginia Tech Carilion School of Medicine, Roanoke, Virginia, USA
[4]Department of Health Systems and Implementation Science, Virginia Tech Carilion School of Medicine, Roanoke, Virginia, USA
[5]Graduate Program in Translational Biology, Medicine, and Health, Virginia Tech, Roanoke, Virginia, USA
[6]Health Analytics Research Team, Carilion Clinic, Roanoke, Virginia, USA
[7]Division of Gastroenterology, Department of Internal Medicine, Carilion Clinic, Roanoke, Virginia, USA
[8]Department of Family Medicine, University of Virginia School of Medicine, Charlottesville, Virginia, USA
[9]Center for Health Behaviors Research, Fralin Biomedical Research Institute at VTC, Roanoke, Virginia, USA

X Michelle S Rockwell @MRockwellRD

Acknowledgements The authors acknowledge Yan Zhang, PhD for data analytics support, Emma G Oyese, MPH for work on the qualitative analysis team, and Jane Burnette for assistance with the literature review.

Contributors MR: conceptualisation, methodology, data collection, data analysis, writing, project administration, supervision. JWE: conceptualisation, methodology, funding, editing and approval of final manuscript, supervision, guarantor. BC, VZ, AS: data collection, data analysis, editing and approval of final manuscript. JKT: data collection, data analysis, editing and approval of final manuscript, project administration. PY, LL, JS, SHP: methodology, data analysis, editing and approval of final manuscript. YW: approval of final manuscript.

Funding Research reported in this publication was supported in part by the National Center for Advancing Translational Sciences of the National Institutes of Health (award number UL1TR003015).

Disclaimer The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Consent obtained directly from patient(s).

Ethics approval This study involves human participants and was approved by the Institutional Review Board of Carilion Clinic (IRB 22-1812). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

ORCID iD
Michelle S Rockwell http://orcid.org/0000-0001-7910-6083

REFERENCES

1 World Cancer Research Fund International. Colorectal cancer statistics. n.d. Available: https://www.wcrf.org/cancer-trends/colorectal-cancer-statistics/
2 Ebner DW, Kisiel JB, Fendrick AM, *et al*. Estimated Average-Risk Colorectal Cancer Screening-Eligible Population in the US. *JAMA Netw Open* 2024;7:e245537.
3 Rockwell MS, Frazier MC, Stein JS, *et al*. A "sludge audit" for health system colorectal cancer screening services. *Am J Manag Care* 2023;29:e222–8.
4 Doherty M, Thom B, Gardner DS. Administrative Burden Associated with Cost-Related Delays in Care in U.S. Cancer Patients. *Cancer Epidemiol Biomarkers Prev* 2023;32:1583–90.
5 Sunstein CR. Sludge Audits. *Behav Public Policy* 2022;6:654–73.
6 Hodson N. De-sludging healthcare systems. *BMJ* 2023;383:2916.
7 Herd P, Moynihan D. Health care administrative burdens: Centering patient experiences. *Health Serv Res* 2021;56:751–4.

8 Kyle MA, Frakt AB. Patient administrative burden in the US health care system. *Health Serv Res* 2021;56:755–65.
9 Hattke F, Hensel D, Kalucza J. Emotional Responses to Bureaucratic Red Tape. *Public Adm Rev* 2020;80:53–63.
10 Want to restore trust in government? Start with customer experience. Brookings. Available: https://www.brookings.edu/articles/want-to-restore-trust-in-government-start-with-customer-experience/ [Accessed 11 Feb 2024].
11 Herd P. Improving Older Adults' Health by Reducing Administrative Burden. *Milbank Q* 2023;101:507–31.
12 How to address the administrative burdens of accessing the safety net. Center for American Progress; 2022. Available: https://www.americanprogress.org/article/how-to-address-the-administrative-burdens-of-accessing-the-safety-net/ [Accessed 12 Feb 2024].
13 Haeder SF, Moynihan D. Race And Racial Perceptions Shape Burden Tolerance For Medicaid And The Supplemental Nutrition Assistance Program. *Health Aff (Millwood)* 2023;42:1334–43.
14 Waldren S, Billings E. A guide to relieving administrative burden: prior authorization. *Fam Pract Manag* 2023;30:13–8.
15 IHI Leadership Alliance. Call to action: reduce waste in the US health care system. Available: https://www.ihi.org/sites/default/files/2023-10/IHI-Leadership-Alliance_Waste-Portfolio-Overview.pdf
16 The White House. Cancer moonshot. Available: https://www.whitehouse.gov/cancermoonshot/ [Accessed 13 Feb 2024].
17 Erickson SM, Rockwern B, Koltov M, *et al*. Putting Patients First by Reducing Administrative Tasks in Health Care: A Position Paper of the American College of Physicians. *Ann Intern Med* 2017;166:659–61.
18 GOV.UK. Bureaucracy busting concordat: principles to reduce unnecessary bureaucracy and administrative burdens on general practice. Available: https://www.gov.uk/government/publications/bureaucracy-busting-concordat-principles-to-reduce-unnecessary-bureaucracy-and-administrative-burdens-on-general-practice/bureaucracy-busting-concordat-principles-to-reduce-unnecessary-bureaucracy-and-administrative-burdens-on-general-practice [Accessed 08 Apr 2024].
19 The White House. Burden Reduction Initiative | OMB. Available: https://www.whitehouse.gov/omb/information-regulatory-affairs/burden-reduction-initiative/ [Accessed 19 Jul 2024].
20 Department of Health & Social Care. Bureaucracy busting concordat: principles to reduce unnecessary bureaucracy and administrative burdens on general practice. 2022. Available: https://www.gov.uk/government/publications/bureaucracy-busting-concordat-principles-to-reduce-unnecessary-bureaucracy-and-administrative-burdens-on-general-practice/bureaucracy-busting-concordat-principles-to-reduce-unnecessary-bureaucracy-and-administrative-burdens-on-general-practice
21 Getting rid of stupid stuff. Available: https://edhub.ama-assn.org/steps-forward/module/2757858 [Accessed 13 Feb 2024].
22 Fetters MD, Molina-Azorin JF. A Checklist of Mixed Methods Elements in A Submission for Advancing the Methodology of Mixed Methods Research. *J Mix Methods Res* 2019;13:414–23.
23 Strengthening the reporting of observational studies in epidemiology (STROBE): explanation and elaboration | annals of internal medicine. Available: https://www.acpjournals.org/doi/full/10.7326/0003-4819-147-8-200710160-00010-w1 [Accessed 25 Feb 2024].
24 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–57.
25 American Cancer Society. *Colorectal Cancer Facts & Figures 2020-2022*. Atlanta, GA: American Cancer Society, 2020.
26 Thatcher EJ, Camacho F, Anderson RT, *et al*. Spatial analysis of colorectal cancer outcomes and socioeconomic factors in Virginia. *BMC Public Health* 2021;21:1908.
27 Harris PA, Taylor R, Thielke R, *et al*. Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform* 2009;42:377–81.
28 Joosten YA, Israel TL, Williams NA, *et al*. Community Engagement Studios: A Structured Approach to Obtaining Meaningful Input From Stakeholders to Inform Research. *Acad Med* 2015;90:1646–50.
29 Adams C, Walpola R, Schembri AM, *et al*. The ultimate question? Evaluating the use of Net Promoter Score in healthcare: A systematic review. *Health Expect* 2022;25:2328–39.
30 Shea JA, Micco E, Dean LT, *et al*. Development of a revised Health Care System Distrust scale. *J Gen Intern Med* 2008;23:727–32.
31 Economic Research Service. *USDA ERS - Rural-Urban Commuting Area Codes*. US Department of Agriculture, 2020.
32 Braun V, Clarke V. *Thematic Analysis: A Practical Guide*. SAGE, 2021:371.
33 Viera AJ, Garrett JM. Understanding interobserver agreement: the kappa statistic. *Fam Med* 2005;37:360–3.
34 Guetterman TC, Fetters MD, Creswell JW. Integrating Quantitative and Qualitative Results in Health Science Mixed Methods Research Through Joint Displays. *Ann Fam Med* 2015;13:554–61.
35 Bodenheimer T, Sinsky C. From triple to quadruple aim: care of the patient requires care of the provider. *Ann Fam Med* 2014;12:573–6.
36 Khullar D. Building Trust in Health Care-Why, Where, and How. *JAMA* 2019;322:507–9.
37 Rockwell M, Stein J, Gerdes J, *et al*. Trust in healthcare and trust in science predict readiness to receive the COVID-19 vaccine in appalachia. 2021. Available: http://deepblue.lib.umich.edu/handle/2027.42/167136 [Accessed 22 Jan 2022].
38 Martin L, Delaney L, Doyle O. The distributive effects of administrative burdens on decision-making. *J Behav Public Adm* 2023;6.
39 Moynihan D, Herd P, Harvey H. Administrative Burden: Learning, Psychological, and Compliance Costs in Citizen-State Interactions. *J Public Adm Res Theory* 2015;25:43–69.
40 Haeder SF, Moynihan DP. Most Americans support minimizing administrative burdens for Medicaid recipients as the public health emergency ends. *Health Aff Sch* 2023;1:qxad001.
41 de Bruijn E-J, Antonides G. Poverty and economic decision making: a review of scarcity theory. *Theory Decis* 2022;92:5–37.
42 Health Affairs Brief. How administrative burdens can harm health. Available: https://www.healthaffairs.org/do/10.1377/hpb20200904.405159/full/ [Accessed 06 Oct 2022].
43 Laura Zatz LM. Americans need help — clear the sludge that gets in the way. The Hill; 2021. Available: https://thehill.com/opinion/white-house/538666-americans-need-help-clear-the-sludge-that-gets-in-the-way/ [Accessed 12 Feb 2024].
44 Soman D, Cowen D, Kannan N, *et al*. Seeing sludge: towards a dashboard to help organizations recognize impedance to end-user decisions and action Toronto, Canada Behavioural Economics in Action at Rotman (BEAR) Report series; 2019. Available: http://www.rotman.utoronto.ca/bear
45 May FP, Yano EM, Provenzale D, *et al*. Barriers to Follow-up Colonoscopies for Patients With Positive Results From Fecal Immunochemical Tests During Colorectal Cancer Screening. *Clin Gastroenterol Hepatol* 2019;17:469–76.
46 Wang H, Roy S, Kim J, *et al*. Barriers of colorectal cancer screening in rural USA: a systematic review. *Rural Remote Health* 2019;19:5181.
47 Zhu X, Weiser E, Jacobson DJ, *et al*. Provider-perceived barriers to patient adherence to colorectal cancer screening. *Prev Med Rep* 2022;25:101681.
48 Malo TL, Correa SY, Moore AA, *et al*. Centralized colorectal cancer screening outreach and patient navigation for vulnerable populations in North Carolina: study protocol for the SCORE randomized controlled trial. *Impl Sci Commun* 2021;2:113.
49 Glass K, Seals A. Patient navigation (PN) for colorectal cancer screening (CRC): Experience in program implementation for underserved neighborhoods of Cleveland, Ohio. *JCO* 2019;37:147.
50 Coverage of certain preventive services under the affordable care act. Federal Register; 2015. Available: https://www.federalregister.gov/documents/2015/07/14/2015-17076/coverage-of-certain-preventive-services-under-the-affordable-care-act [Accessed 20 Dec 2021].