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Original Article

Barriers to Colorectal Cancer Screening for people with spinal cord injuries and/or disorders: A qualitative study

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ABSTRACT

Background: Limited research has shown people with spinal cord injuries and/or disorders (SCID) are less likely to be up to date with colorectal cancer (CRC) screening and therefore more likely to be diagnosed with advanced stage CRC compared to people without SCID.
Objective: The aims of this study were to assess knowledge about CRC, CRC screening, and self-reported barriers to CRC screening for people with SCID.
Methods: Interviews with 30 individuals with SCID were conducted using a semi-structured interview guide, audio recorded, and transcribed. Coding was performed using a hybrid approach of inductive and deductive analysis. Thematic analysis was used to identify, review, and modify themes and sub-themes.
Results: Themes identified included barriers to CRC screening, such as socioeconomic, health system, transportation, psychological, and environmental or accessibility barriers. While most respondents were able to describe one CRC screening method (usually colonoscopy), knowledge of other screening modalities was limited. Low CRC literacy and misinformation about CRC screening appeared to increase respondent association between CRC screening and colonoscopy. While most respondents associated CRC screening with colonoscopy, almost half reported the colonoscopy preparation was the most substantial barrier to screening.
Conclusions: In addition to addressing identified barriers such as accessibility and transportation, communication, and prevention interventions should be specifically targeted to ensure all people with SCID are informed about appropriate and various modalities and the benefits of screening. Specific, evidence-based guidelines on the use of stool specimens first with follow up direct visualization, if needed, should be developed for this population.

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Introduction

Even though colorectal cancer (CRC) is the second leading cause of cancer-related mortality, screenings do not meet the recommended rates or frequency.[1–8] Kao et al. (2016) postulated that individuals with spinal cord injuries or disease (SCID) have a lower risk of CRC compared to the general population.[9] However, other research suggests that people with SCID may actually be at an increased risk for many reasons, including behavioral and lifestyle risk factors, such as obesity and physical inactivity.[10–13] In addition, other authors suggest that the use of laxatives and insufficient sensation in the abdomen may lead to an increased risk of CRC for persons with SCID.[13] Finally, people with SCID may be at heightened risk of neurogenic bowel and other colorectal disorders, such as irritable bowel syndrome, which have been linked to an increased risk of CRC.[14–16]

Despite these risk factors, notable disparities in screening rates between people with and without SCID are documented.[2,17] Individuals with SCID have lower CRC screening adherence as

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reported by Lofters et al. (2018, 36.7%) and Deroche et al. (2017, 44.14%) compared to 62.4% in the general population.[2,17] As life expectancies for people with SCID increase with medical advances, there is a corresponding need to ensure guideline-concordant CRC screening within this population.[2,3,6,13,17] Integrating CRC screening for people with SCID includes potential challenges, which may impact both patient and provider perspectives. For example, Stillman et al. (2014) reported 76.9% of people with SCID were seen in offices with inadequate examination tables, 69.4% of offices did not have transfer equipment, and 85.2% of their study sample remained in their wheelchair during examinations.[18] Colonoscopy preparation and complications during the procedure may lead people with SCID to forgo screening. Colonoscopies may pose specific challenges for people with SCID, such as frequent transfers during preparation, autonomic dysreflexia, and colon perforation due to abdominal sensation deficits.[7,17,19] Neurogenic bowel, which people with SCID are more prone to, can lead to inadequate bowel cleansing and may limit colonoscopy diagnostic capabilities.[17,19–22] Research has shown colonoscopy can be effective for people with SCID if bowel preparation regimens are extended for multiple days.[20,23] However, Barber et al. reported that 4 of their 18 participants with SCID required a nasogastric tube placement to complete their preparation.[24]

While the literature identifies broad barriers for people with any disability that may contribute to low CRC screening rates for people with SCID, it is unclear which of these factors are applicable to this population and which barriers are most influential from the individual with SCID's perspective, and why. Additionally, current research has not fully examined what people with SCID want, value, or need in a CRC screening program. This study uses interviews conducted with individuals with SCID to understand their perspectives and experiences surrounding barriers to CRC screening.

Methods

Selection and recruitment of participantsd

Participants were identified through the Healthcare Enterprise Repository for Ontological Narration (HERON) at the University of Kansas Health System (KUHS).[25] Two separate requests were submitted for people with SCID: (1) no evidence of CRC screening at KUHS and (2) evidence of CRC screening at KUHS. Participant eligibility was based on age (50–75 years at the time of their visits), diagnostic code(s) for SCID (see Table 1), and being in the Frontiers Research Participant Registry. Purposive sampling, based on CRC screening status, insurance status, and sex, was used to focus on a very specific population and topics which were central to the research aims.[1,26–28]

Study sample

Thirty individuals with SCID participated in interviews. The study cohort consisted of 16 female participants and 14 male participants, all of whom had health insurance (see Table 2). Most of the cohort were white and either single or divorced. All participants lived within 20 miles of KUHS, spoke English, and had ages ranging from 50 years to 78 years. The study cohort had diverse spinal cord disabilities: amyotrophic lateral sclerosis, spina bifida, various paralytic syndromes, and other SCIDs. Available demographics and pseudonyms used for the participants are outlined in Table 3.

Table 2
Final sample of participants with SCID interviewed.

	CRC Screening	No CRC Screening
	N = 16	N = 14
Sex		
Male	7	7
Female	9	7
Insurance		
Commercial	4	5
Medicaid	5	3
Medicare	7	6

Table 3
Themes and sub-themes.

Participant	Sex	Age	Race	Insurance
Alice	Female	72	White	Medicare
Robert	Male	54	White	Medicare
John	Male	72	White	Medicare
Mike	Male	56	White	Medicare
William	Male	69	White	Medicare
Mary	Female	62	White	Commercial
Shirley	Female	66	White	Medicare
Joan	Female	67	White	Commercial
Ruth	Female	78	Black	Medicare
Helen	Female	62	Two Races	Medicaid
Judith	Female	62	Black	Medicaid
Dorothy	Female	50	White	Medicaid
Ronald	Male	57	White	Medicaid
Harry	Male	72	White	Medicare
Minerva	Female	65	White	Medicare
Nancy	Female	57	White	Commercial
Barbara	Female	58	White	Medicaid
Fred	Male	52	White	Medicaid
George	Male	60	Black	Medicaid
Dean	Male	68	Black	Medicare
Liz	Female	51	Black	Medicare
Charles	Male	66	Black	Medicaid
Carol	Female	54	White	Medicare
Bill	Male	68	Other	Commercial
Joyce	Female	77	White	Medicare
Paul	Male	66	White	Commercial
Virginia	Female	62	White	Commercial
Jack	Male	71	White	Commercial
Ken	Male	60	White	Commercial
Lois	Female	65	White	Commercial

Data collection

The interview guide (see Appendix A), covered the following domains: primary care, pre-appointment routines, transportation, social support, patient-provider relationship, decision-making, CRC

Table 1
Diagnostic codes and descriptions used to identify patients with SCID.

ICD-9-CM	ICD-10-CM	Description of Codes
343.2, 344.0x, 344.1x, 780.72	G80.0, G82, R53.2	Paraplegia and Quadriplegia
767.4x, 806.xx, 907.2, 952.xx	P11.5, S14, S24, S32, S34	Injury to spine, spinal cord, or nerves
741	Q05	Spina bifida
335.2	G12.21	Amyotrophic lateral sclerosis

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and CRC screening awareness, and overall health status. The interview guide was formulated via a thorough review of existing literature, adapted for layman's terms, and edited for final approval through the KUHS IRB. At the beginning of each interview, all participants signed an informed consent. All interviews were in-person, audio recorded, lasted between 30 and 120 min, and were conducted at a location chosen by respondents.

Data analysis

Data were analyzed using the six-step thematic analysis as outlined by Braun & Clark (2006).[29] Initially, data familiarization occurred by reading and listening to the interviews before the coding process. After data familiarization, we developed our codebook (see Appendix B) and used a combined inductive and deductive coding approach on all interviews to address our research aims and allow for unexpected phenomena to emerge.[30] Coding was completed by the primary author with the senior author's oversight. Two main themes emerged while coding: "Common Barriers to Colorectal Cancer Screening" and "Colorectal Cancer Screening Awareness" with sub-themes aligned under each main theme (see Table 4). We identified the essence of these themes, how themes relate, and how sub-themes relate to their parent themes and interacted with each other. Sub-themes are provided with representative quotes in Table 5 and described below. Analyses for this study were conducted using NVivo Version 11.4.1.1064.

Results

Results in this paper are the participants' recorded responses and perceptions of their experiences and interactions with their environment, the healthcare system, and their primary care providers.

Common barriers to Colorectal Cancer Screening

Common barriers to CRC screening are not specific to people with SCID; however, research has shown people with SCID are differentially affected by these barriers compared to people without SCID.[18,31,32] In addition, some barriers, such as socioeconomic, psychological, and the lack of accessible transportation and facilities (exam tables, etc.) are especially problematic for people with disabilities, including people with SCID.

Socioeconomic

Fyffe et al. (2011) contend socioeconomics may affect persons with SCID more compared to persons without SCID due to poorer health and an enhanced occurrence of financial adversity.[33] Most respondents reported they and others could not afford to pay for all their healthcare needs. *Paul,* a 66-year old male living with radiating lower back pain into his lower leg, described the complications of navigating health insurance and the constraints of living on a fixed-income:

> *What do[es insurance] cover? How much is out of my pocket right now instead of just showing me a bill for a couple thousand dollars? … I can't afford $600 for a pill.*

Healthcare system

Many participants reported healthcare system barriers, such as access and continuity of care, which are noted in the literature.[32] When asked what would make it easier to get needed healthcare, *Helen*, a 62-year old female with paraplegia describes the frustration of accessing healthcare: *Access to the doctors. Sometimes there's long appointment times really far out. Robert*, a 54-year old male living with severe spinal cord deformities, reported access to the same provider was not easily attainable: *Only if I make my appointment six months out.*

Transportation

Some participants in the study cohort were able to drive; however, most needed specialized services to get to and from medical appointments. While transportation barriers may be seen in numerous populations, insufficient access to appropriate and adapted transportation is a significant barrier for people with SCID.[32] When asked what they would do if their first transportation option was not available, many respondents would cancel their appointments. *Ronald*, a 57-year old male who had a traumatic back injury in 2002 and lives with debilitating arthritis and anxiety, said he would cancel an appointment if he could not get a ride: *I just have to cancel the appointment until I can get somebody to take me. Charles*, a 66-year old male who has severe lower extremity weakness due to a spinal cord injury, was extremely succinct when asked if his initial transportation options were not available: *Then*

Table 4
Themes and sub-themes.

Themes and Sub-Themes	Description of Themes and Sub-Themes
Theme One: Common Barriers to Colorectal Cancer Screening	
Sub-Theme One: Socioeconomic Barriers	Income, education, or employment issues that impact healthcare, such as fixed-incomes and insurance
Sub-Theme Two: Healthcare System Barriers	Access to healthcare providers, equipment, and procedures in a timely manner
Sub-Theme Three: Transportation Barriers	Includes access to and availability of transportation or mobility devices needed to go to and from medical appointments
Sub-Theme Four: Psychological Barriers	Mental or emotional states, such as stress and anxiety, which impact health
Sub-Theme Five: Environmental and Physical Barriers	Natural or manmade barriers, such as stairs or non-height adjustable examination tables
Theme Two: Colorectal Cancer Screening Awareness	
Sub-Theme One: Colorectal Cancer Knowledge	What the participants reported they knew about colorectal cancer
Sub-Theme Two: Colorectal Cancer Screening Knowledge	What the participants reported they knew about colorectal cancer screening methods
Sub-Theme Three: Origins of Colorectal Cancer Screening Knowledge	How participants learned about colorectal cancer screening
Sub-Theme Four: The "Gold Standard" and Misinformation about Screening	Colonoscopy is considered the most effective screening by many in the United States. Participant's screening perceptions and knowledge that was not completely accurate
Sub-Theme Five: Why the "Gold Standard" May Not Work for People with SCID	People with SCID face many difficulties with colonoscopy including frequent transfers, skin management, and multi-day preparation

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Table 5
Key sub-themes and representative quotations from study participants.

n[a]	Sub-theme	Representative quotes
20	Socioeconomic	• "What do[es insurance] cover? How much is out of my pocket right now instead of just showing me a bill for a couple thousand dollars? … I can't afford $600 for a pill." • "The government gives me $30 a month personal spending and that's it." • "They took everything away from me in order [for me] to get health care literally." • "I'm glad [the academic medical center] didn't kick me out when I was broke."
17	Healthcare System	• "Access to the doctors. Sometimes there's long appointment times really far out. It's discouraging getting into someone new." • "Only if I make appointment six months out." • "It was a long time before I got my supplies…I think it was about four or five months into this year that you know I was not getting my supplies." • "Not being able to get appointments." • "I shouldn't have to wait 60 min between a visit from the nurse and a visit from the doctor."
21	Transportation	• "I just have to cancel the appointment until I can get somebody to take me." • "Then 'Charles" won't go to the doctor." • "Waiting on [transportation] can be anywhere from an hour and sometimes it was 4 h" • "Because I don't walk down the hill for that city bus. I can't get back up that hill." • "You gotta plan like 2 h ahead of time and then of course you gotta wait on the other end a lot longer."
9	Psychological	• "I'm not going to [beat] this disease but I'm going to give it one hell of a fight because I see these people that come in with ALS and they only got a year to live, well, you give up. Something happens to you mentally." • "I mean because it's more me. In my mind. It's not a priority because I really don't wanna be here. I don't wanna be here. I pray every night. I'm tired, tired, lonesome, ready to go. Tired of the pain, tired of the headache, tired of the noise, just tired." • "When your life revolves around doctors that's pretty depressing. That's a big point when you go to the doctors so much."
21	Environment and Physical	• "I think the one thing that kinda fries me about the medical profession is they don't have, once you're in the doctor's office yourself they're cramped, and they got no way for you to get up on the table because they're high tables so there's no way to accommodate wheelchair folks." • "I don't have a problem getting to where I'm going its people that act like I'm not in this wheelchair and we are at the elevator. Now, you can walk upstairs asshole, I can't. You don't get on the elevator and look at me like, there's room, you should have let me go on first. You all don't want me to swing this chair around and tear up everybody legs, so you know what I tell them," I'll get the next one." Yeah, that happened to me yesterday." • "So, a full exam no because you have to have a Hoyer lift to transfer people like me on to a bed, mat whatever and then we're all so different. Most of us are frail to roll people and put them in situations you're risking not being able to breathe, breaking bones, just all kinds of headaches you just don't think about when you see somebody in a chair."
28	Colorectal Cancer Knowledge	• "Not a whole lot. I just know it's not good." • "Not too much, not too much about it at all." • "I know it's more predominant, my understanding it is more predominant in male as it is female." • "Nothing, not really." • "Surprisingly, less than I could or should."
28	Colorectal Cancer Screening Knowledge	• "I think I heard something but I'm not sure some kind of, but I'm not really sure some advertising someplace or something." • "I know they don't start checking for it until your about 40 years, 50 years of age. Then they tell you to have a colorectal exam about every five years, something of that nature." • "None, unless they have to do when they check your prostate if they can feel you have an enlarged prostate maybe they can see at point they can see if you have [a] colorectal situation." • "I know there's different ways to do it. I know you can take the pill. I know that you can do the … normal scanning and you do it every what is it? Every seven years or something like that." • "I think that there's a blood test also but I'm not familiar with it."
27	Origins of Colorectal Cancer Screening Knowledge	• "I think [masked] might have said "how long has it been since you've had one", and "we think you should." • "Yeah, my sisters told me." • "Within the family, [they asked] "are you checked?" • "I've seen it on TV." • "I see an advertisement on TV that's called the CG and I [think] it is for Col[oguard]®."
28	The "Gold Standard" and Misinformation about Screening	• "They offered the other but from a reliability standpoint the only way is going in there and do the follow-up." • "There's a little postcard they sent out and you can put some stool on the card and send it off and they'll tell you what they found but I don't think that would be very reliable for someone who's got polyps." • "When I first started talking to them, they pushed the colonoscopies … They were strongly suggesting it. Twenty-five years ago, that was, you know, a big push if you were coming up on 50." • "But colonoscopy is the gold star. I've heard of GI doctors say that many times." • "They have to do an MRI."
27	Why the "Gold Standard" May Not Work for People with SCID	• "Because the preparation, that's the main thing and the aftermath. It's too hard to get to the toilet sometimes…Well, I wish there was a way that you didn't have to do all that preparation because to me if you can't get up and down because the toilet." • "I couldn't go through the prep now...It was ugly [before]. You're cleaning yourself out…it's just messy…I wouldn't do it now…because they would have to move me. I couldn't help them at all." • "I know my last one I couldn't get clean…because I've had chronic constipation for so long and because I'm on a lot of stimulants…It's like they have to go above and beyond to get cleaned out really well … That could be one reason why people don't get screened, because they heard about the prep part and [ask] 'Why should I have to go through that?'" • "My pressure sores wouldn't allow it. The less I put on my family just can't do it." • "I've had to have as many as four days of prep … And, that's means not eating for four days…It's pretty brutal. You don't feel well. You can't do much."

[a] Number of individuals whose responses were coded within this sub-theme.

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"Charles" won't go to the doctor.

Psychological

Stress and other psychological factors play an integral role in the overall health of people with SCID. People with spinal cord injuries experience psychological disorders two times more often than the general population.[34] Psychological factors, such as anxiety, stress, or being despondent, kept several participants from being screened. *Ruth*, a 78-year old female who has severe back pain and walks with an irregular gate, has given up hope and the will to live:

> *It's not a priority because I really don't wanna be here. I pray every night. I'm tired, tired, lonesome, ready to go. Tired of the pain, tired of the headache, tired of the noise, just tired.*

Environment and physical

According to Ronca et al. (2020) environmental barriers were reported by 68% of people with SCID; most of our participants who required the use of mobility assistive devices also reported environmental and physical barriers.[32] *Helen* discussed one of her frustrations about the physical barriers wheelchair users encounter during medical appointments:

> *No, I think the one thing that kinda fries me about the medical profession is they don't have, once you're in the doctor's office yourself, they're cramped, and they got no way for you to get up on the table because they're high tables, so there's no way to accommodate wheelchair folks.*

Fred, a 52-year old male who experienced a spinal cord injury which caused paralysis in his lower limbs, reported he had not been examined outside of his wheelchair or had an accurate weight assessed in nearly a decade:

> *So, a full exam no because you have to have a Hoyer lift to transfer people like me on to a bed…and then we're all so different. Most of us are frail. To roll people and put them in situations, you're risking not being able to breathe, breaking bones, just all kinds of headaches you just don't think about when you see somebody in a chair.*
>
> *They take your word for your weight. I went through a number of years where I had no idea what my weight was … And then when I was hospitalized, they put me on the bed, and I weighed 260 something. On my chart it said I was 320. "What happened? You lost 60 pounds overnight." What happened was I hadn't been weighed in about 8 years and my weight changed.*

Colorectal Cancer Screening Awareness

Barriers related to CRC screening awareness and knowledge were the most noteworthy in the interviewed population. Indeed, this barrier likely played an important role in non-screening rates for those interviewed than did other common barriers described earlier. CRC screening requirements vary by which stool-based and/or direct visualization tests are recommended (see Table 6).

Colorectal cancer knowledge

Overall, most participants' knowledge of CRC was limited. When asked what she knew about CRC, *Nancy*, a 57-year old female whose spinal cord injury causes considerable pain and requires use of a cane, reported what many interviewees echoed: *Not a whole lot. I just know it's not good.* Limited knowledge of CRC came from having friends and family with a history of CRC. *Virginia*, a 62-year old female who is a liver transplant survivor with a spinal cord injury that radiates pain to her lower extremities, explained she had a family history of CRC: *My grandmother had rectal cancer. Lois*, a 65-year old female who had severe anxiety and lives with chronic pain due to her spinal cord injury, recounted why she is screened more often: *My father died of colon cancer, so instead of every ten years I have [colonoscopies] every five. Carol*, a 54-year old female who has chronic fatigue syndrome and a spinal cord injury had a father and sister with CRC: *Well, it's kinda a personal thing because my dad had colon cancer and my sister did.*

Colorectal Cancer Screening Knowledge

When participants were asked what they knew about CRC screening specifically, almost all described a specific modality. *Alice*, a 72-year old female with degenerative disc disease and agoraphobia, first stated she knew nothing about CRC screening but eventually described two methods:

> *Nothing…I know they go up your rectum…[there's] a thing you can use at home to test for cancer in your poop.*

Harry, a 72-year old male who has a spinal cord injury from a 30-foot fall, was able to describe two screening modalities: *Instead of going in and doing the colonoscopy you can do a sample and mail it in.*

Origins of Colorectal Cancer Screening Knowledge.

All participants reported their CRC screening awareness came from several entities: primary care provider (PCP), family and friends, and advertisements.

Primary care provider

One-third of respondents interviewed reported their PCP discussed CRC screening:

> *Seamus: I think she was the one that set up the colonoscopy…*
>
> *Lois: I see a gynecologist…he sends home the hemoccult test with you…I see a GI doctor pretty regularly and he orders a colonoscopy.*

Family and friends

Barbara, a 58-year old female who injured her spine after a fall due to fatigue from her liver transplant stated she heard about CRC screening from family: *Yeah, my sisters told me. Carol* added: *Within the family, [they asked] "are you checked?"*

Advertisements

Nearly one-third of participants reported they had heard of CRC screening through advertisements. When asked about CRC screening, Shirley, a 66-year old female with acute pain and multiple SCIDs responded: *Shirley: I've seen it on TV…It's supposed to be easier than a colonoscopy. Alice* added: *I see an advertisement on TV that's called the CG and I [think] it is for Col[oguard]®.*

The "gold standard" and misinformation about screening

In 2000, the American College of Gastroenterology (ACG) made the recommendation to its members that colonoscopy be performed every ten years as the preferred choice of CRC screening,

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Table 6
Characteristics of colorectal cancer screening strategies (recreated from screening for colorectal cancer US preventive services task force recommendation statement).

Screening Method	Frequency[a]
Stool-Based Tests	
gFOBT	Every year
FIT[b]	Every year
FIT-DNA	Every 1 or 3 years[c]
Direct Visualization Tests	
Colonoscopy[b]	Every 10 years
CT Colonography[d]	Every 5 years
Flexible Sigmoidoscopy	Every 5 years
Flexible Sigmoidoscopy with FIT[b]	Flexible sigmoidoscopy every 10 years plus FIT every year

Abbreviations: FIT, fecal immunochemical test; FIT-DNA, multitargeted stool DNA test; gFOBT, guaiac-based fecal occult blood test.

[a] Strategy yields comparable life-years gained (ie, the life-years gained with the noncolonoscopy strategies were within 90% of those gained with the colonoscopy strategy) and an efficient balance of benefits and harms in CISNET modeling when lifetime number of colonoscopies is used as the proxy measure for the burden of screening, but not if lifetime number of cathartic bowel preparations is used as the proxy measure.

[b] Applies to persons with negative findings (including hyperplastic polyps) and is not intended for persons in surveillance programs. Evidence of efficacy is not informative of screening frequency, with the exception of gFOBT and flexible sigmoidoscopy alone.

[c] Strategy yields comparable life-years gained (ie, the life-years gained with the noncolonoscopy strategies were within 90% of those gained with the colonoscopy strategy) and an efficient balance of benefits and harms in CISNET modeling.

[d] Suggested by manufacturer.

thus making it the "gold standard."[35,36] Many respondents referred to colonoscopy as the best screening option because it is more reliable or accurate. *John*, a 72-year old who has Kennedy's Disease said:

> *They offered the other [gFOBT] but from a reliability standpoint the only way is going in there [colonoscopy] and do the follow-up.*

Joyce, a 77-year old female who has acute radicular pain post spinal cord surgery, shared her belief gFOBT is not as reliable as colonoscopy:

> *There's a little postcard they sent out and you can put some stool on the card and send it off and they'll tell you what they found, but I don't think that would be very reliable for someone who's got polyps.*

Jack, a 71-year old male with severe pain in his lower back and hip post spinal cord surgery, discussed how his PCPs pressed for a colonoscopy: *When I first started talking to them, they pushed the colonoscopies.* While interviewing *John*, he described a conversation with a "GI doctor," and how they informed him about colonoscopy being the "gold star" of CRC screening:

> *But colonoscopy is the gold star. I've heard [the] GI doctor say that many times. You bring up other alternatives to it and he's like, "Well yeah they have this and that, but you know colonoscopy is the gold star."*

When asked about CRC screening, participants responded with information they received or perceptions they have regarding the screening process. *Helen* believed, as several other respondents, that stool modalities were less reliable: *I think a stool specimen isn't reliable.* Participants reported a multitude of screening timelines. When discussing colonoscopy, *Virginia* stated they should be performed more frequently than guideline standards: *So, that's something that's done every other year?*

Other participants, such as *Harry* and *Nancy*, were under the impression all screening modalities occurred on the same timeline:

> *Harry: I know they don't start checking for it until you're about 40 years…Then they tell you to have a colorectal exam about every five years…*
>
> *Nancy: Every seven years…*

Fred tried to describe CRC screening and confused CRC screening with another potential cancer screening method: *I think that there's a blood test [PSA] but I'm not familiar with it.*

When asked what they knew about CRC screening, most people tied CRC screening specifically to colonoscopy. *Minerva,* a 65-year old female with a severe back pain radiating to multiple sites stated: *I would think a colonoscopy. Jack* added: *Usually it's what colonoscopies are for.*

Participants reported not wanting to be screened because they did not want to undergo a colonoscopy, and apparently were not aware of alternatives. *Dorothy,* a 50-year old female living in a long-term care facility and dealing with the hardships of paralysis shared:

> *Dorothy: Here's my issue. I don't know when I'm gonna have a bowel movement…I really have no desire to drink that stuff and have someone clean up the mess…*
>
> *Fred discussed not being screened due to colonoscopy preparation: Absolutely can't take the test because I can't be on the pot for 24 hours.*

Why the "Gold Standard" May Not Work for People with SCID.

While the ACG has called for wide-spread colonoscopy use, people with SCID may not tolerate the colonoscopy preparation. When participants were asked why they would not complete another colonoscopy or to describe the colonoscopy screening process, most participants reported the preparation was emotionally and physically taxing. *Helen* described a process of doing the preparation and not making it to the restroom in time: *It's too hard to get to the toilet sometimes. John* discussed not being able to go through the preparation process due to being in a motorized wheelchair. He talked about his fierce independence and not being able to help maneuver himself into position:

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I couldn't go through the prep now...It was ugly [before]. You're cleaning yourself out…it's just messy…I wouldn't do it now… because they would have to move me. I couldn't help them at all.

Carol and *Lois* described the physical and emotional toll of a multi-day colonoscopy preparation. *Carol* discussed how the preparation might be an important barrier to the receipt of CRC screening:

Carol: I know my last one I couldn't get clean…because I've had chronic constipation for so long and because I'm on a lot of stimulants…It's like they have to go above and beyond to get cleaned out really well … That could be one reason why people don't get screened, because they heard about the prep part and [ask] "Why should I have to go through that?"

Lois: I've had to have as many as four days of prep … And, that's means not eating for four days…It's pretty brutal. You don't feel well. You can't do much.

Discussion

Although many studies have addressed CRC screening barriers for all patients or patients with any disability, this study fills a gap in the literature specific to CRC screening for people with SCID.[1,2,4,5,8,37–40] Many of our respondents described the hardships of coordinating transportation, especially if their primary mode of transportation was not available. Several respondents reported psychological factors impacted their care and CRC screening adherence, such as being emotionally drained and not caring about their health or healthcare any longer. People with SCID, who are wheelchair users, reported numerous environmental barriers to include parking, non-adjustable exam tables, desk height, room size, and the inaccessibility of scales for accurate weight measurements. People with SCID may have competing diseases and comorbidities that take priority over CRC screening for both the individual and PCP. Future studies should examine interactions between PCPs and people with SCID to determine if competing healthcare priorities emerges as a barrier to CRC screening.

Respondents did not report any differences in their overall experiences with barriers to CRC screening based on whether they had received screening or not. A possible explanation is all respondents were from one geographic location and were seen at KUHS. In other words, all participants were subject to the same barriers before, during, and after their medical appointments. Further research is needed to determine if this is a local phenomenon or connected with SCID status.

Patient knowledge of CRC screening came from three main sources: PCPs, family and friends, and advertisements. Almost all respondents were able to describe one CRC screening modality. This may be explained by: (1) people with SCID may have more contact with the healthcare system and therefore have more opportunities to learn about CRC screening, (2) PCPs and other healthcare professionals within KUHS may be more proactive about communicating with people with SCID about CRC screening, and (3) most interviews occurred during an up-tick of Cologuard® commercials before CRC awareness month in March. Further research should be conducted to substantiate these explanations.

Colonoscopy has been considered the "gold standard" in the US since the ACG proclaimed patients should be screened using colonoscopy in 2000.[35] While not every participant identified colonoscopy as the "gold standard," one respondent reported a physician said it was the "gold star" and several participants stated it was preferable to other modalities. Interestingly, nearly half of the interviewed participants referred to CRC screening as colonoscopy and approximately one-quarter of those interviewed did not want to complete CRC screening because they equated screening with colonoscopy. Future studies should examine barriers specific to colonoscopy preparation, colonoscopy examinations, and extended preparation regimens within the population.

People with SCID may not be able to tolerate colonoscopy preparation. Almost half of all participants interviewed described the preparation as emotionally or physically draining. Several respondents discussed never undergoing colonoscopy preparation due to an inability to transfer fast enough from their wheelchairs. Other participants described the taxing effect of a multi-day cleanse which was needed because of neurogenic bowel or other bowel disorders. People with SCID may be at increased risk of complications during the colonoscopy procedure due to sensation deficits.[20] Colonoscopy may be high yield for certain patient populations, but colonoscopy may not be the most appropriate modality for people with SCID. Further examination of screening modalities, other than colonoscopy, is warranted to help increase CRC screening adherence in this at-risk population.

Most studies in the area of CRC screening and disabilities rely on patient surveys and do not delineate between the broad category of physical disability and the more specific category of SCID. While there are several current studies on people with SCID and the receipt of CRC screening, this is the first to evaluate self-reported barriers to CRC screening among people with SCID. National surveys do not capture data from institutionalized individuals, including patients in long-term care facilities. This study was able to include two patients who live in long-term care facilities and one patient who lives in an assisted-living facility. Future studies should examine if disparities exist in CRC screening adherence and barriers to screening between individuals who are and are not classified as institutionalized, especially people with SCID.

Several limitations of this study should be considered along with the findings. First, the interview guide and responses were descriptive in nature. Thus, it may not be feasible to use for recommendations on new strategies to increase CRC screening in the overall population with SCID. However, the recommendation to explore alternative modalities to increase CRC screening is an essential step to begin developing public health interventions for this population. Second, the findings are biased towards barriers for people with SCID as no comparison interviews were completed with people without SCID. However, some of the barriers, such as transportation, CRC screening awareness, and colonoscopy preparation, may be applicable to people without SCID. Further research is needed to investigate if the barriers identified by this study are transferable to people in other geographic regions. Lastly, selection bias was a limitation due to the process of participant recruitment. Only participants who opted into research studies were contacted and only the participants willing to be interviewed were part of the study cohort. Of the 466 eligible people with SCID, 131 people were called to schedule the 30 interviews. While responses from the 30 participants were consistent, which indicates data saturation, more research is warranted to verify these findings.

Conclusion

There were no discernible differences in the experiences of CRC screening barriers reported by participants based on prior screening or insurance status. A large portion of the study population had low CRC knowledge unless they had encountered it through family or friends. Most participants were able to describe one screening modality, with colonoscopy being the top modality discussed. Many of the participants would not undergo CRC screening because they equated it with colonoscopy and reported

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both emotional and physical distress during the colonoscopy preparation. To ensure all people with SCID, who are eligible for CRC screening, are informed about the benefits of screening, communication and prevention interventions should be specifically targeted for this population. This targeted prevention intervention should include a clinical exam with the PCP focusing on the relative benefits and risks of non-detection with screening modalities other than colonoscopies and potential complications specific to this population. Complications with colonoscopy preparation and procedures should be taken into account when developing more effective prevention strategies. Moreover, the US Preventive Services Task Force should consider development of specific, evidence-based guidelines on the use of stool specimens first followed up with direct visualization, if needed, for this population. In addition, PCPs should be mindful of other barriers often encountered by this population, including environmental, socioeconomic, and co-occurring psychological conditions.

People with SCID are at an increased risk for some common maladies and have further risks for SCID-related complications. It is vital that healthcare for people with SCID include preventive care to improve health outcomes and decrease preventable illnesses. Barriers to healthcare exist for people with SCID, thus, PCPs and people with SCID must acknowledge and strive to minimize these barriers through patient-centric care and the use of open communication geared to maximize health outcomes and address patient concerns.

Disclaimer

The views expressed in this article are those of the authors and do not reflect the official policy or position of the United States Air Force, Department of Defense, or the U.S. Government.

Declaration of competing interest

No conflicts of interest or funding are being reported.

Appendix C. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.dhjo.2020.100950.

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