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Service Providers and Researchers Perceptions on Colorectal Cancer Burden and Screening Programme in South Africa: A Qualitative Study

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Abstract

Background: Accurate estimation of colorectal cancer (CRC) cases in South Africa is pivotal to policy and service delivery planning and disease control. It is estimated that CRC will increase up to 8,000 per 100,000 populations by 2030 in the country. Noting the lack of population based CRC registry, the burden may be under estimated. There is scarce knowledge on perceptions of researchers and service providers of CRC on burden, screening interventions, key challenges facing in South Africa and recommendations on CRC control. The study aims to explore perspectives on CRC burden screening and outline recommendations for CRC control.

Methods: A descriptive and explorative qualitative study was conducted using a semi-structured interview guide through telephonic or virtual interviews with 15 participants from multi-disciplinary backgrounds from three big metropolitan cities of South Africa. Data were analyzed using a thematic framework.

Results: CRC was perceived as one of the critical cancers in South Africa although due to a National surveillance system the CRC burden it is not accurately reported. Older Caucasians with a family medical history and young black men were mentioned, as high risk groups. The participants confirmed that South Africa does not need a CRC national screening programme, but, expressed a need for a coordinated targeted programme to better align the public and private health sector screening practices. Monitoring CRC screening guidelines compliance; barriers in screening access, lack of awareness, distance to screening facilities, lack of demand generation by service providers, lack of medical insurance, equipment failure and scarcity, unpleasant and invasive procedure and poor health seeking behaviour were some of the challenges cited by participants. The participants recommended improvement in targeted screening based on evidence; promotion of screening campaigns, risk assessment to be conducted for early referral, expansion of screening facilities to reduce inequalities and provider capacity building to strengthen competencies and skills.

Conclusion: The findings highlight multiple perspectives on CRC burden and screening in South Africa. Policy makers and programme managers should be aware of these perceptions to improve quality of care; explore alternative testing methods, demand creation approaches to improve CRC awareness and reduce the inequities in screening access.

Keywords: Colorectal cancer; Burden of colorectal cancer; Screening; Colonoscopy; Qualitative study; Cancer; South Africa

Abbreviations: (CRC) Colorectal Cancer; (COREQ) Consolidated Criteria for Reporting Qualitative Research; (DoH) Department of Health; (FIT) Faecal Immunochemical Test; (gFBOT) Guaiac Faecal Occult Blood Test; (MSI) Microsatellite Instability; (WHO) World Health Organisation

Background

The WHO Global Cancer Observatory data of 2018, showed that colorectal cancer (CRC) incidence rate, in South Africa, is 14.4 per 100,000 populations, categorised as the top six leading cause of cancer related deaths in South Africa (7.6 per 100,000 population). It is estimated that the new CRC cases in South Africa will increase up to 8,000 per 100,000 populations by 2030 [1]. The data also indicates lack of gender differentiation between males and females in terms of the incidence rate (7.3 and 7.1 per 100,000 for males and females respectively). There is low incidence in Sub-Saharan Africa [2], it is advocated that African countries tailor cancer screening programmes, prevention and control interventions based on local and geographical patterns of risk factors and cancer burden profiles, instead of implementing national CRC screening policies [3-5].

To better understand the CRC burden and reduce health disparities in relation to CRC screening, it is important to have population-based CRC registry, a responsive health system, innovations and robust research framework that support the cancer care continuum [6-10]. The population based registry and the national CRC screening programme, currently, do not exist in South Africa, to accurately identify population at risk, CRC burden, geography patterns to inform the comprehensive CRC health care response [11-13] stated that should there be rising CRC incidence in Africa that it is estimated, this will require appropriate allocation of resources to facilitate identification and treatment.

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Noting the lack of population based CRC registry, the burden may be under estimated thus limiting extensive and detailed inclusion of evidence based interventions at population level scale. Localised CRC screening interventions are implemented in South Africa [14]. Some studies conducted in South Africa and Zimbabwe concurred the feasibility of CRC screening among patients with inherited CRC in both countries [15]. A systematic review of clinical trials has shown identified benefits of CRC screening in the reduction of CRC-specific mortality [16,17]. Doubeni, in 2018, also supported colonoscopy as an effective screening test for reducing mortality from both left-sided and right-sided colon cancers.

The most common procedure used for CRC screening is the colonoscopy in South Africa, guided by the Standard Operational procedure document published by the CRC society in the country noting the lack of a national screening policy. Other tests, such as faecal occult blood (guaiac and immunological test) are also performed to symptomatic and high risk groups. However, the colonoscopy has challenges, in terms of coverage, access and uptake. Hence, there have been different screening modalities implemented by both public and private health sectors in South Africa including a financial incentive, rewards through medical insurance and mobile CRC colonoscopy services [15,18]. Localised epidemiological studies have been published and are used to inform the provision of targeted CRC screening services [14,19,20,21]. Conducted a cross-sectional study among 170 471 insured population (2007-2011) from one insurer, to identify predictors to screening guidelines. The study found that 1.1% had adherence to CRC screening guidelines. Plan type, gender, provincial residence, and incentivized wellness programme were associated with screening services utilisation. The presence of the microsatellite instability (MSI) has been found as one of the key characteristics of CRC presentation. A retrospective study of samples taken and CRC diagnosed between 2011-2012 in South Africa were tested for the presence of MSI. The study found that twelve percent of samples from patients presented with MSI, with increased frequency in black (15%), young, with MSH2/6 protein loss compared to other ethnic groups (8%) [19]. Stefan (2015), called for focused research on the role of diet and other factors to cancer risk to better understand the ethnic differences on CRC incidence [21].

The CRC screening completion rate, the rate of detection of colonoscopic abnormalities, histopathological analyses of biopsies, surgical intervention and colorectal cancer deaths were used to compare the quality of a mobile screening service to that of a stand-alone endoscopic unit, in South Africa. It was found that the quality of a mobile service was similar to the units as there was no significant difference identified in terms of completion and early CRC detection rates; the negative predictive value for the mobile was 100% and accuracy rate was 97%, meeting the international standard for CRC screening (19).

Brand (2018), conducted a retrospective study using private healthcare funder's database to determine CRC presentation, general management patterns and overall survival in the South Africa between January 2008 to 31 December 2015. He found that of the 3 412 cases included in the study, 66% were diagnosed with CRC only and 34% had liver (LM) or pulmonary metastases (PM) with the mean age of 64 years (range 21-97), and 55% were males. The analysis of the Durban colorectal cancer database, in 2009, to compare the clinic-pathological patterns of colorectal carcinoma between patients that utilises public and private healthcare systems in South Africa found that of 491 patients diagnosed with CRC, 319 has used the private healthcare; 258 were male; most patients that used public healthcare were younger; had advanced disease and had a lower resection rate than those that used the private healthcare system. However, no differences were noted regarding the anatomical site distribution of the tumour [22].

While there is adequate evidence regarding burden, treatment and screening methods, there is little evidence published regarding perspectives on burden, current screening perspectives and awareness from patient, provider, policy or programme managers and general population. Hence, more research is needed to gain insight on the burden and screening approaches that can be explored in South Africa. This study may aid a deeper understanding of how the participants view the CRC burden, current screening practices and what should be done to better manage the CRC burden in South Africa. Moreover, it may provide valuable information to guide future intervention targeting raising awareness of CRC and reducing barriers to screening.

Hence, the aim of the qualitative study sought to find out perspectives from the participants on colorectal cancer burden and screening in South Africa, with the purpose to identify factors influencing inequalities in screening. The objectives were to: (1) explore the burden of CRC and the needs for national screening programme; (2) identify the characteristics of sub-groups with more and less access to CRC screening; (3) list the types of CRC screening being used and what are benefits of these compared to others; (4) identify factors that influence access to screening services; and outline the recommendations to improve access and increase the participation in CRC screening.

Methods

Design and setting

An explorative qualitative design with individual telephonic or virtual interviews was used to explore experienced, meaning and perspectives and identify themes and patterns to create deeper understanding of CRC burden.

Participants

The recruited participants were from multi-disciplinary background including various academic and clinical backgrounds, including oncology surgery, public research, non-governmental organisations and public and private medical health care. All potential participants had to be currently and directly involved and or published on the CRC prevention, treatment and care.

The Participants were identified from published papers on CRC and were mainly located in Gauteng, KwaZulu-Natal and Western Cape provinces, representing the three big cities within each province, namely, Cape Town, Johannesburg and Durban. Email requests for an interview were sent; with the informed consent form and interview guide attached and proof of ethical approval were forwarded via email when requested by the potential participants. Two reminder e-mails were sent to non-responders within a week of the first e-mail.

In total, forty-five participants were identified and invited for interviews by e-mail or telephone in English that included a summary of aims and objectives of the study. Fifteen participants (33%) responded to the email and were subsequently interviewed. The interested respondents chose the date, time and platform for the telephonic or virtual interview. Telephonic, Skype, Zoom platform were used to conduct the interviews. The interviews were conducted by telephone (2 interviews) or using Skype (1 interview) and virtual zoom or Microsoft teams (12 interviews).

The 15 participants comprised of eight females and seven males. The participants included five researchers; three policy-makers, three medical practitioners; three worked for cancer focused non-governmental organisations; and one focused in the area of radiology. The majority (six) were based in Johannesburg, South Africa (Table 1).

Sampling

Purposive sampling approach was used to identify experts on CRC to be interviewed as key informants. Further, a snowball sampling technique was conducted to increase the number of respondents. The participants were asked to suggest others that could add valuable insights in line with the aims of the study, using the snowballing sampling method, at the end of the interview.

Participating Sectors	Focus Area of Expertise and experience	Number interviewed in different provinces	Gender
Medical	Experts in disease clinical or surgical management in public and private sector	Johannesburg=1	Male
		Cape Town =1	Male
		Durban=1	Male
Radiology	Expertise in diagnostic radiology	Johannesburg=1	Male
		Cape Town=0	
		Durban=0	
Research	Expertise in research on colorectal cancer including epidemiologist, human genetics, health economics	Johannesburg=2	Male and Female
		Cape Town=2	Male and Female
		Durban=1	Female
Non-profit organisations/	Experts that are patient advocates for or provide services to oncology patients (CRC in particular) or survivor representatives	Johannesburg=1	Female
associations		Cape Town=1	Female
		Durban=1	Female
Policy Makers/Programme managers	Experts in policy or guideline development and service delivery (private and public sector)	Johannesburg= 1	Male
		Cape Town=0	N/A
		Durban= 2	Female and Male

Table 1: Participant Characteristics: area of expertise and experience, geographic location and gender.

Data collection

Data were collected during August, September and October 2020 using a semi-structured interview guide to structure the interviews. The development of the interview guide was informed by the CRC literature reviewed from South Africa in terms of burden of disease and published papers on CRC screening methods used in the country. The guide was developed to gather perceptions of Participants on the CRC burden in South Africa, CRC surveillance, options for CRC screening with enablers and barriers to screening, CRC awareness and recommendations for CRC control, training, research and patient care. It sought perceptions on CRC screening including:

- CRC Burden in South Africa
- Characteristics of the patients affected
- Type of CRC data available
- National Control Response
- Perception on Mass CRC screening
- Screening uptake or participation
- Type of screening available in South Africa
- Barriers in access of CRC screening
- Recommendations for CRC screening

The guide was appraised by the two co-investigators experienced in qualitative study methods and development of semi-structured interviews as data collection method. At the beginning of the interview, the participants were given information on the background of the interviewer and the aim of the study and interview. On average the interviews lasted about 30 to 45 minutes. At the end of each interview, an interviewer summarised the key responses and allowed the participants to confirm and add any data to supplement to ensure a comprehensive representation of the views. Interviews were only stopped once data saturation was reached, when no new themes emerging from interviews [23]. The same interview guide was used to ensure dependability of the interviews and transcribing verbatism.

Data analysis

All the responses were transcribed verbatim. The analysis process was in two phases. The first phase involved reading responses twice by researchers to draw focus on the collected data and attempt to identify inclusive thematic framework. Two researchers (SM and GVH) independently coded two responses and compared these through discussion to finalise and align the key themes emerging from the responses that assisted with the final thematic analytic framework, until agreement is reached on the thematic structure that was used for the rest of the interviews conducted and analysed by SM, to ensure credibility [24]. The second phase included a deep dive reading of the documented responses to identify specific secondary and tertiary sub-themes, which was reviewed with interpretation of meaning compared; similarities were identified independently and discussed to combine after agreement by both SM and GVH. To support and justify key themes identified, we have included direct quotations from participants presented in italics to ensure transferability and to adhere to COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist [25].

Results

The analysis resulted in identification of number themes under component of enquiry, as outlined in (Table 2).

The themes emerged under key subject components aligned to the objectives that reflected detailed descriptions of the primary themes.

The Participants mentioned that data was drawn from the pathological reports or hospital admission database.

The Participants mentioned about the lack of national screening

CRC Component	Description of Identified Themes
CRC Burden	· CRC is one of the critical cancers in the country
	· Lack of National Surveillance Data to accurately estimate the burden
	· CRC is under-reported
Characteristics of the patient affected	· Race: White
	· Age: 50 yr. and older
	· Family history
	· Pre-existing conditions
	· Tumor staging
Data availability	· Localised focused on minority groups
	· Hospitalised or pathology data
National Control programme	· None existence of national response
	· Public Health response fragmentation
Perception on Mass CRC screening	· Inapplicability of mass screening
	· Competing burden of other cancers and communicable diseases
	· Response for screening is economically driven
	· Screening guidelines exist
	· Failure of monitoring compliance
	· Effectiveness of targeted screening
	· Awareness and Knowledge of CRC as key factor of screening
Screening uptake or Participation	· Health care provider as drivers of awareness; uptake and referrals
Type of screening available in South Africa	· Gold standard-colonoscopy
	· Others tests used include gFOBT and FIT
Barriers in access of CRC screening	· Lack of national screening programme
	· Lack of medical insurance
	· Distance of facilities
	· Poor infrastructure
	· Poor health seeking behaviour
	· Invasive procedure
	· Provider degree of competencies and skills

Table 2: CRC Screening Themes per CRC screening component of enquiry

programme and advocated for targeted screening.

They also identified a lack of population based registry to be the consequence of under-reporting of CRC as well as lack of awareness by the citizens which affect health seeking behaviour and delays the time to speedy identification of CRC.

The Participants also highlighted the importance of conducting colonoscopy, perceived to be a gold-standard, to those with symptoms or suspects based on family and medical history.

Besides the lack of the national screening programmes, some of the barriers mentioned included lack of adherence to screening guidelines; lack of access to screening services in the public healthcare sector, long distances to services and limited service provider competencies.

Perceptions on CRC burden

The participants expressed CRC to be one of the top five cancers in South Africa, yet, highlighted that it is under-reported due to lack of population based surveillance system. However, all perceived South Africa to have a low burden of CRC, as compared to cervical, lung and breast cancer. Some participants emphasised that the population statistics do not reflect the reality, based on what is being observed on a daily basis at their facilities. One participant stated: “They may say that there is low CRC incidence, however, in my hospital, every week I see about five to ten patients coming for screening”.

Perceptions on characteristics of the patients affected

The CRC was perceived to affect Caucasian and people older than 50, some with family history of CRC. According to seven participants, with three having medical backgrounds stated that the majority of patients that are screened and diagnosed with CRC are mostly Caucasians South Africans aged 50+ years.

However, three participants also stated that they see all racial groups and cannot differentiate the burden based on race alone, particularly, relating their experience based on the private sector where the screening uptake was also influenced by the type of medical insurance plan and reward plan a client has for enrolling in various types of screening activities. One participant stated: “Well, we see all patients from different races, as most clients gain points for taking screening tests, including CRC, especially with one particular medical insurance. So, the motivation is getting rewards or points while they are also being reassured of their health status”.

A handful of participants mentioned to have observed the rising number of CRC diagnosis among the Black population, especially, young people, in particular, males. One participant stated: “Where I work, I see young Black men, referred for screening and get a positive diagnosis that I would not have suspected. After the first few encounters, I have learned to speak about and assess risks for CRC, whenever I see young black men”.

The other difference mentioned was the cancer staging phase, with white population mostly diagnosed at the early onset of the disease, while the black populations are diagnosed at an advanced stage of disease. The vast majority of participants mentioned that screening for

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diagnosis is usually performed in the private sector facilities. They further mentioned that the ease of access to screening is facilitated by medical health insurance enrolment for patients using private sector screening facilities, compared to the majority of those that use public sector facilities, whom the participants categorised as having a low socio economic background.

Perceptions on data availability

Due to unavailability of population based CRC data, the majority of participants (n=9) perceived that CRC burden could be underestimated and may be on the rise for certain groups based on CRC screening clinical data from hospitals. All participants mentioned the need to obtain accurate data on CRC burden. However, some (n=4) stated that this will require a shift of resources to CRC surveillance through national screening programmes in the country. One KI mentioned that "CRC is amongst the top five malignancies in South Africa, hence, the need to have a population based registry is justified."

The other participants were concerned about the health planning in the absence of accurate data, stating: "It's hard to identify who is affected, what age and where they live. This makes it hard to plan and allocate the scarce resources when we are unsure about the burden".

South Africa is currently relying on the pathological based cancer registry, to cover the gap on the lack of population based cancer registry. One participant expressed uncertainty with CRC incidence country estimates, stating; "We will continue to do piecemeal, there and there, based on the professional and personal interests and no one at the Health Department will do anything about it, as we are not able to pull all the data together and monitor this yearly to estimate the burden and advocate for national coordinated response".

Perceptions on national CRC screening

When asked about the national screening, the participants reported that it does not exist, however, screening is performed in the country and can be categorised, regardless of its fragmented nature, by sectors (public or private).

The public sector was perceived to be uncoordinated, while the response from the private sector, mentioned by a handful of participants (n=5) was perceived to be economically driven. The participants stated: "In the public sector, health providers do not even speak or mention anything on CRC, even when treating clients with gastrointestinal track (GIT) symptoms, such as piles, that have not been managed even with repeated visits. At least, in the private sector, if the patient is 50+, the doctor will mention the need for screening, even if the patient is not really at risk to rule out any possibilities, and at the same time, their medical practices or hospitals also benefit financially from each colonoscopy performed".

Some participants mentioned that while there are more opportunities for screening in the private sector screening, however, there may be challenges with compliance to the screening standard operational procedures (SoP). One participant stated: "Promotion and frequency of CRC screening is very high in the private sector, but I am unsure if all the doctors adhere to the screening guidelines, considering the financial gains per procedure".

The participants with medical background also mentioned that South Africa lacks the national CRC risk assessment and screening SoP to guide clinical assessment and frequency of CRC screening and adherence. One participant, stated" we just get to know who is affected at the point of diagnosis, the risk assessment is often not done".

To support clinicians, the participants had mentioned that South Africa CRC Society for clinicians had provided guidance on CRC screening based on the World Health Organisation (WHO) guidelines yet they pointed out that there are no mechanisms for monitoring compliance. Two participants pointed out that: "The frequency of screening depends on the discretion of the doctor managing the patient", while the other said" Frequency depends on the approval of the health insurance for the member to undergo the screening".

The participants providing services in the public sector mentioned the gatekeeping mechanism to monitor compliance. One participant said: "Due to limited resources, we only do the screening based on the provincial guidance and the justification is reviewed before approval of the colonoscopy".

Perception on mass CRC screening

When asked regarding the need of a mass CRC screening campaign, all participants believed that there is no need for a national campaign in South Africa noting low burden of the disease. The need to focus on other types of cancer that affect the population the most including cervical and lung cancer as well as communicable diseases such as HIV was expressed to demonstrate competing interests and focus for the country.

All participants endorsed targeted screening for the most at risk population. This strategy was viewed as the most cost-effective for South Africa. For this strategy, it was reported that it both could be requested by patients as much as it could be promoted by the attending doctors.

One participant considered equity in resource allocation, stating that: "will need to take into account the health status of the population, especially the HIV prevalence, the limited access to health care and the resource-constrained health system".

Another stated:" human and financial resources are required to implement the population based screening programme, we just do not have that kind of budget".

Two participants mentioned that "Colonoscopy is both doctor driven or promoted and among well-informed clients at risk, they demand it. It really depends on affordability and willingness to pay".

Perceptions on CRC screening uptake

The participants stated that CRC screening is targeted and dependent on a number of factors including age eligibility, family history of CRC, personal history of stomach or gastro-intestinal signs and symptoms, and direct referral by a medical doctor based on the risk assessment.

The majority of participants (n=9) emphasised that the demand for screening usually originates from personal awareness, knowledge and experiences of patients and medical doctor awareness, experience and competency to consider CRC screening upon medical assessment of a patient. Awareness and knowledge of CRC from friends and family were mentioned as key drivers for screening.

In addition, some participants (n=5) stated that the majority of population are unaware of CRC, hence do not think of the need for and benefit of screening as they do not know anyone who had undergone screening, as the CRC burden is low in South Africa. While other participants (n=4) indicated that in general, people do not screen unless they feel unwell.

One participant stated,” Lack of knowledge about colorectal cancer and the benefits of screening not being promoted and most people not being aware of CRC at all, so, may see it as ‘unnecessary’ to go through screening when they feel well”.

Another stated: “In South Africa, people are reluctant to seek medical care; they put it off until they cannot anymore, and so, early detection of cancer is not possible”.

Five participants mentioned that raising awareness was the responsibility of medical personnel, doctor and nurses, who are supposed to know about CRC and are supposed to conduct risk assessment and refer clients that are suspects for screening. They further expressed concerns that even the health professionals do not know anything about CRC, expressed by one participant in the following manner: “the blind leads the blind, in this situation”. Another stated: “Doctors and nurses have a duty to recommend CRC screening as part of general health assessment, in that way; more people will consider taking it”.

Perceptions on type of screening available in South Africa

The participants listed three types of CRC screening services, including guaiac faecal blood test (gFOBT), faecal immunological test (FIT) and colonoscopy. One stated: “Early diagnosis is important to identify cancer early, as this affects the type of treatment and the outcomes and effectiveness and cost related to both”.

The majority of participants viewed colonoscopy as superior to the other two tests. One participant mentioned that the introduction of screening facilitates early diagnosis and this is best value for money in cancer control, especially in South Africa, where there is high burden of both communicable and non-communicable diseases. The majority of participants also mentioned that while the yield and sensitivity of FIT and gFOBT are high, the specificity may be compromised. As one participant stated: “You get a lot of false negatives, unlike colonoscopy”.

Almost all participants (n=12) noted that the majority of doctors prefer to perform colonoscopy as the first test to ensure accuracy of results as this facilitates urgent treatment decision making and immediate actions to the results, without delay caused by second appointment booking of patients for further investigation. One participant stated: “Some patients stay very far from the screening services such that they may not be able to return for follow-up investigation, so, it’s good to get everything done whilst they are still at the facility. In that way, you reduce the time for the cancer to advance in the body”.

Concerns regarding high cost associated with colonoscopy were also raised and the fact that there are not enough experts that can perform endoscopy.

Perceptions on barriers in access for CRC screening

All participants reported that South Africa does not have a national CRC screening programme, however, CRC screening is promoted and supported by doctors for at risk population groups and by family members with a history of CRC. Most barriers described by participants are tabulated in (Table 3) below.

Other barriers highlighted by participants included lack of health insurance, unaffordability of costs associated with screening, fear of the unknown; denial of the risk or health problem and low perception of risk to motivate people to demand screening for CRC.

Low capacity and competencies of medical doctors to conduct CRC screening in the public sectors, which results in low yield and poor quality of screening services, were also cited by a few participants (n=2).

Thematic barriers	Example Quotes
Long waiting list for CRC screening	Interview 1=*”In private sector, clients just book with their medical aid card, given the date immediately and get done without waiting, whereas, in the public sector, patients are booked and provided dates as far as 6 months to a year in the future, with some never showing up when the actual date finally arrives or they are diagnosed with advanced cancer which affects the survival rate”*
Malfunction of the equipment for screening	Interview 4: *” There is either poor maintenance of the screening equipment in the public sectors, or limited equipment in the public sector, which limits the number of screenings done per day”.*
Long distance of CRC screening facilities	Interview 5: *“People move from their towns to another town to get the screening or drive long hours to get to the facility.*
Colonoscopy is perceived to be invasive	Interview 3: *“Colonoscopy is the best but not everyone wants to do it, perhaps they can consider less invasive methods of screening”*
Poor health seeking behaviour	Interview 8: *“People put off from seeking care when not feeling well. They wait until they can’t bear it anymore”.*
Anxiety related to the screening procedure	Interview 10 *“Some people feel anxious and do not like having anything going up their rectum”*
Poor knowledge and lack of awareness about colorectal cancer and the benefits	Interview 15: *“At least, people must know about CRC and what to do to reduce risks and if they have history and are at risk be referred immediately for screening. This can be easily done at primary health care level even when screening is not available for general population”*

Table 3: Thematic barriers to CRC screening

Discussion

The paper describes the views of policy-makers, researchers and service providers of CRC services, from a qualitative study, to better understand the views and recommendations on CRC burden and current screening practices including barriers in access in South Africa. The section below discusses findings based on the consolidated components from the interview guide.

Burden, people affected and data availability

The participants viewed CRC as one of the most critical cancers in South Africa. Hence, their views are supported by the Global Cancer Observatory (2018), stated that colorectal cancer (CRC) incidence rate, in South Africa (SA), is 14.4 per 100,000 populations, with the incidence rate of 7.3 and 7.1 per 100,000 for males and females respectively. It is the 5th most frequent cancer in South Africa and is estimated that by year 2030, the number of new cases will increase by 39% while the number of deaths will increase by 40% in 2030 in SA [1].

The availability of high-quality local data to prioritise and evaluate cancer control efforts cannot be over-emphasised (2). There is lack of population based cancer registry in South Africa, as mentioned by participants. Most recently, South Africa is in the process of establishing a cancer surveillance programme using thee population-based cancer registry based on the protocol for data collection that was published in 2019 by the National Institute of Communicable Disease of South Africa [26].

This initiative will reduce CRC under reporting and hesitancy to act decisively on CRC control, improve data quality and projections to assist policy-makers and programme managers develop an appropriate public health CRC control response.

Factors affecting CRC screening

Our study suggests that CRC screening is influenced by many factors, including epidemiological data; patients and family history; availability of screening facilities in the public and private sector or resources; eligibility criteria, presence of medical insurance, staff knowledge and competence; type of screening; age, ethnic background and awareness and knowledge of CRC [19,27-34].

Poor knowledge of and lack of awareness about colorectal cancer and its benefits, invasive procedure and poor health seeking behaviour, were most commonly cited by the participants, as barriers to uptake of CRC screening. Lambert (2009) Suggested that mass CRC screening should not be supported or advocated for in Sub-Saharan Africa, where the CRC burden of disease is low [3].

Raising public awareness, integration of CRC screening with other screening services, was offered as solutions to some of the barriers by the vast majority participants. In addition, the participants and other authors also placed emphasis on SoP adherence, service provider competencies, quality of care, availability and functionality of screening equipment and a need to innovate to identify more choices of tests to conduct screening [5,35-38].

Prior studies have reported age, gender, marital status, level of education, race or ethnicity, physicians' gender, recommendations and competencies, limited staff, usual source of care, health insurance, income, presence of chronic diseases, family history of colorectal cancer, inadequate knowledge and fear of finding cancer as obstacles to the uptake of screening colonoscopy resulting in CRC incidence and mortality inequities [39-45].

In contrast, Honein-Abou Haidar, stated that the beliefs, attitudes, and motivation influences intent and decisions for CRC screening uptake, while, McLachlan,stated that education and advise from the doctor as well as organisational issues also affect intentions for action. In addition, word of mouth, directly from the patients that have gone through screening, can also promote screening, as suggested by the participants and Bass, 2011. Some studies had identified that the barriers for CRC screening uptake are very similar to those reported for breast and prostate cancer screening and that the Health Belief Model can be used to address these social determinants of health as means to increase the uptake of screening [46-48].

This is consistent with the studies by [32,45,49] that reported that the uptake is better when recommended by the medical doctor and it is suggested that this be coupled with the evidence based information's highlighting the benefits and importance of screening. Therefore, as mentioned by Kaminski, 2020, there is a multiple interplay of factors influencing actions by patients, providers, and health organisations affecting CRC screening uptake. Hence,17, advocates for integration of interventions addressing both individual and health systems barriers. Most studies also found out that removing cost related barriers increased opportunities for screening uptake among patients with low socio-economic status [36,50,51].

Other modalities to increase uptake and yield, including mailing personal invitation letters for CRC screening to all eligible clients or sending electronic invitations, as suggested by Camilloni, 2013, currently implemented in developed countries, may be less effective in South Africa and other developing countries due to a lack of infrastructure and logistic systems. However, the author also endorsed the strategy of sending invitations by medical doctors, that has proven to be effective and accepted to influence uptake and is also currently implemented as a strategy in South Africa.

CRC screening methods

Invasiveness of colonoscopy was also mentioned as a barrier to examination; hence, Participants recommended innovations to diversify screening methods or procedures. Other studies, have cited the preparation and the procedure as uncomfortable and awkward [30,35,44,52,53]. Hence, Tayyeb, 2020 motivates for blood biomarkers, as a potential alternative for individuals as they are less invasive and most people are used to have their blood collected as part of medical care [54]. However, currently, there are also guaiac faecal occult blood tests or FITs available and used 31 however, mentions there are challenges with adherence of these as compared to colonoscopy, as, Liang, 2016 found that adherence to repeat colonoscopy was better [55]. Almog, 2008 reported that the Israeli population preferred gFOBTs for an average risk population and colonoscopy for high-risk individuals [27]. The literature on this topic indicates that each screening procedure has its own unique role and may be preferred or suitable for some and not suitable for others, thus affecting the adherence [34,56,57]. Hence, Bass, 2012 and Carethers 2020 promote marketing of benefits and increasing coverage by ensuring equity and availability of facilities to increase uptake of screening [58,59].

Barriers to uptake and recommendations to improve the national response

Other important findings to highlight were the participants' recommendations. The recommendations focused on approach to creating demand for screening; case finding strategies; diversity of screening methods, increasing access to reduce inequities; policy development and strengthening monitoring, evaluation and research. These recommendations bring an important perspective and valuable inputs from experts for the Department of Health (DoH) to consider and inform the national cancer control framework on CRC as this aspect of cancer is not fully addressed [60]. The inputs provided can also facilitate closer consultations between DoH and CRC experts and can be a catalyst for the development of a comprehensive CRC control plan in South Africa. Schliemann D 2020 published a protocol on the scoping review for CRC screening interventions in low and middle-income countries to build capacity and assist with synthesis of the status of CRC screening programmes to inform policy and practice [61] (Table 4).

Limitations

The limitations with our study, is that we had reached out to and invited nearly 50 potential participants, however, a fifteen sent a positive response. Many proved hard to reach and we were unsuccessful to track them especially during the height of covid-19 lockdown regula-

CRC Screening Component	Recommendations	Examples of quotes
Demand Creation	Raise Awareness at community level and primary health care facilities targeting general public Using word of mouth to share Information on CRC	“People must be convinced that by taking CRC screening, they can benefit from the screening’ [Interview 6]. “The patients hear about it from the experiences of family and friends”. Interview 9]. “Raising awareness in communities where local or regional cancer registry data is being collected”. Interview 11].
	Targeted health promotion to high risk population Promotion of screening as a routine without the need to feel unwell	“Clients with known history should be linked to institutions for screening immediately to promote early detection of CRC”. Interview 3]. “Target health promotion for at risk clients and their relatives to initiate early screening”. Interview 14]. “Provide client-centred care in order to identify those clients that require screening and further investigations”. Interview 8]. “CRC is usually silent, so, clients feel well and they do not have any warning signs that may directly lead them to think they might have CRC. So, even when they hear about screening, they feel it is not applicable to them”. Interview 1].
Case Finding	Use a risk assessment tool Identify Signs and symptoms for screening Off patient centred screening Health provider capacity building	“A risk analytic tool could be used by nurses for those with any gastric related problems to identify suspects for CRC, just like screening for TB”. Interview 2]. “Integrated screening of CRC with other non-communicable diseases using a risk assessment tool could be beneficial. For an example, the tool can be used by the nurse clinician at primary health care level to identify CRC suspects for referral to tertiary or regional levels institutions for further investigation”. Interview 5]. “Patient centred investigations need to be considered”. Interview 7]. “A malignant colorectal tumour should be suspected for any child with signs and symptoms of intestinal obstruction, intractable abdominal pain, alteration in bowel habits and gastrointestinal bleeding”. Interview 3]. “Practicing pathologists can be assisted through a case base learning to improve diagnosis”. Interview 12]. “Train doctors to conduct accurate endoscopy”. Interview 1]. “Improve quality of care. It is critical for CRC screening programme success in the public sector”. [Interview 7]. “Provide orientation to health care providers to conduct risk assessment to facilitate and strengthen linkages between primary health care and regional level where appropriate investigation can then be conducted”. [Interview 13].

Screening procedure	Integrate with other screening for non-communicable diseases Diversity of procedures (non-invasive) to increase uptake and adherence Combination, hierarchical screening Concerns on bowel preparation prior to the procedure	“Imaging plays a significant role in the detection, diagnosis, staging and follow-up of colorectal carcinoma”. [Interview 7]. “Screening tools that are available for general population, must be non-invasive, user-friendly widely distributed, must have high sensitivity and specificity, attract interests, and increase compliance”. [Interview 5]. “Blood biomarkers are superlative candidates for cancer screening”. [Interview 12]. “Investigation of tumour tissue, gut microbiota and bacteria DNA have potential to bring new knowledge that could inform new technologies for CRC screening”. [Interview 9].
		“Combination use of blood-based inflammatory markers as the first screening strategy can be used and supported by the conventional colonoscopy as most clients are familiar with blood samples drawn instead of colonoscopy”. [Interview 12]. “Most clients are reluctant to undergo bowel preparation, feel embarrassed and are uncomfortable with someone or something inserted in their rectum”. [Interview 3].
Screening Access	Equitable access and distribution or allocation of screening facilities Strong referrals between levels of care within the health system Access through physician referrals	Facilities that have screening services should promote these services to raise awareness in communities within the catchment area”. [Interview 4]. “Policy-makers must ensure there are services in all provinces to improve geographic access for CRC screening”. [Interview 9]. “Target provider and individual-related barriers, reduce external and system level barriers, provide more opportunities for screening”. [Interview 8]. “There should be strong linkages and referrals between the public health levels in the system to ensure that those at risk or suspects eventually access appropriate screening at regional and tertiary levels as services are located at those levels”. [Interview 7]. “Most clients in the private sector either do it as part of screening for rewards linked to the medical insurance or they are referred by their primary physicians, to rule CRC out the suspicions if they have any GIT symptoms”. [Interview 3].
Policy Development and Implementation	Improve health systems blocks for CRC control (Human resources, equipment, service delivery) Active engagement and consultation between policy –makers and researchers/medical experts Use of evidence to inform policy, quality of care and programmes on CRC control Lower age of screening for certain groups based on evidence	“Support efforts towards improving the CRC screening infrastructure and equipment”. [Interview 4]. “To improve skills and competencies, include assessors for colonoscopy and specialists to be certified annually”. [Interview 15]. “Improve staff retention by offering incentives within the public health sector”. [Interview 8]. “Active engagement and consultation between policy, programme managers with experts on CRC is critical for appropriate planning, equity in distribution of services and improving patient quality of care”. [Interview 9]. “If it were possible, to advise the CRC society, to start earlier than 50yrs, if possible, we should start at 30 years for certain groups e.g. black men”. [Interview 10].
Monitoring, Evaluation and Research	Expand research to identify other technologies	“Support the public-private partnerships to establish a central repository on CRC screening for analysis to inform national responses “ [Interview 1]. “Identify biomarkers of multiple groups (inflammatory markers, vascular damage markers, molecular and circulating LPS), that are associated with CRC. By understanding the interactions, this could assist in the development of screening tools, technologies and strategies for early detection of CRC and this could potentially offer a variety of testing platforms and wider choices for clients to choose testing methods that best suit their preference”. [Interview 11].

Table 4: Recommendations by Participants on CRC Screening

tions, when most people were working virtually from home. Hence, snowball sampling, proved to be somehow effective, especially when the email of referral was attached however, 40% of people reached through this sampling approach also did not respond and 20% stated that they were no longer in the field of enquiry hence could not participate. However, we advocate that the sample size was adequate to respond to the aim of the study and generate new knowledge on CRC in South Africa because, of the close monitoring of the sample size during data collection according to the [62] framework for power; a well-framed aim and objectives; diverse expertise and experiences connected to the tertiary institutions and large public teaching hospitals and private health hospitals; gender balance of participants; diverse geo-location of participants improving generalisation and external validity [63]; a literature informed interview guide that stimulates dialogue, and rigorous thematic analysis process.

However, purposive sampling method was used, focusing on published authors in peer reviewed journals and cancer service providers, from three big cities may have introduced selection biases and findings may be affected by their unique perspectives, opinions, type of health information and expertise and experiences they are exposed to in their respective context that may be completely different from others. Although a summary of responses were given prior to ending the interview, transcripts were not shared to check for concurrence and ascertain credibility [64]. Expanding the pool to include other experiences and expertise on CRC (pharmacists, immunologist, pathologist, palliative care and stoma-care therapist) may have better contributed to diverse views.

The implications are that we have to learn new techniques to create demand for participation in research within the covid-19 context to overcome poor response rate challenges. More effective recruitment strategies may need to be explored. The interviews were conducted in English, although the interviewer is fluent, English is the second language, and hence, some responses or nuances of the native language may have been lost the culturally-relevant meaning in translation [65].

Conclusion

This study is the first and only qualitative study in South Africa that examines perceptions of key informants on CRC burden and screening, to ascertain its role in South African context, identify the barriers and facilitators to CRC screening and highlight recommendations based on the views from policy makers, researchers and service providers.

The key findings in this qualitative study indicate that CRC is viewed as one of the most threatening cancers in the country. Further, the lack of National Surveillance Data to accurately estimate the burden is acknowledged as one of the aspects causing it to be under-reported. One of the key finding, contrary to what is commonly reported on CRC epidemiology in South Africa, was that participants had observed CRC burden among young and black patients without any medical or family history of cancer. Moreover, the study also supports the recommendation that there is no need for a national CRC screening programme at this stage in South Africa, but, rather a need for a coordinated targeted CRC screening programme to ensure equity and address the challenges identified affecting current screening practices in the country.

Our findings support the notion that accurate data, access to facilities and availability of diverse screening methods are all fundamental to the provision of a quality and integrated CRC national targeted response.

The findings also highlight multi-facet factors affecting inequalities in CRC screening and can be used by policy makers to inform planning of a programme of action at primary health care level to reduce the inequalities and inequities. Furthermore, the findings highlight the current gaps in screening methods and service delivery that may inform future research and service planning in particular, in the public sector to improve the current targeted CRC screening programme for South Africans at high risk.

Geo-mapping CRC burden to available screening services is also crucial to health planning; human resource capacity building, budgeting, and health communication to raise CRC awareness among all people, in particular, those that may be at higher risk. This could also facilitate planning for equity in the establishment of appropriate infrastructure enabling the utilisation of services, especially, at the time when the country is moving towards the roll-out of the national health insurance.

Further research is needed to better understand and capture the interplay between CRC burden, treatment and support between health services providers and patients and their relatives. Patient and their relative's perspectives need to be captured to improve quality of care and ensure equity of supporting services. In addition, information on the knowledge, attitude and practices of health providers could assist policy-makers and programme managers to better structure a national response in particular, at district level, noting that currently there is no coordinated national targeted response.

Ethical Considerations

Three researchers, SM, GVH and MH were involved in the conceptualization of the study and SM and GVH in the development of the interview guide, in English, and interviewing process. All three investigators were involved in data analysis and writing of the paper. Ethical approval was obtained from the University of Antwerp, Belgium and Pretoria, South Africa (Reference numbers: 20/11/127 and 434/2020). All participants provided verbal consent before the individual interviews; were assured of confidentiality and a right to withdraw anytime during the interview.

Consent for Publication

Not applicable

Availability of Data and Materials

Transcripts without personal identifiers used for this paper will be made available from the corresponding author on reasonable request.

Conflict of Interest

The authors declare that they have no conflict of interest. Three researchers, SM, GVH

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Authors Contribution

Conceptualisation SM GVH; methodology – SM, GVH; analysis SM, GVH, MH writing review and editing SM, GVH, MH.

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