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Delays in seeking, reaching and access to quality cancer care in sub-Saharan Africa: a systematic review

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ABSTRACT

Objectives Late presentation and delays in diagnosis and treatment consistently translate into poor outcomes in sub-Saharan Africa (SSA). The aim of this study was to collate and appraise the factors influencing diagnostic and treatment delays of adult solid tumours in SSA.

Design Systematic review with assessment of bias using Risk of Bias in Non-randomised Studies of Exposures (ROBINS-E) tool.

Data sources PubMed and Embase, for publications from January 1995 to March 2021.

Eligibility criteria Inclusion criteria: quantitative or mixed-method research, publications in English, on solid cancers in SSA countries. Exclusion criteria: paediatric populations, haematologic malignancies, and assessments of public perceptions and awareness of cancer (since the focus was on patients with a cancer diagnosis and treatment pathways).

Data extraction and synthesis Two reviewers extracted and validated the studies. Data included year of publication; country; demographic characteristics; country-level setting; disease subsite; study design; type of delay, reasons for delay and primary outcomes.

Results 57 out of 193 full-text reviews were included. 40% were from Nigeria or Ethiopia. 70% focused on breast or cervical cancer. 43 studies had a high risk of bias at preliminary stages of quality assessment. 14 studies met the criteria for full assessment and all totaled to either high or very high risk of bias across seven domains. Reasons for delays included high costs of diagnostic and treatment services; lack of coordination between primary, secondary and tertiary healthcare sectors; inadequate staffing; and continued reliance on traditional healers and complimentary medicines.

Conclusions Robust research to inform policy on the barriers to quality cancer care in SSA is absent. The focus of most research is on breast and cervical cancers. Research outputs are from few countries. It is imperative that we investigate the complex interaction of these factors to build resilient and effective cancer control programmes.

INTRODUCTION

The cancer control agenda has globally received a high level of political recognition.[1] [2] In sub-Saharan Africa (SSA), with an age standardised incidence and mortality rate of 128.2 and 87.2 per 100 000 people respectively, cancer is becoming a leading public health problem.[3] There is growing emphasis that the successful translation of commitments to support cancer control policy into substantial reductions in cancer morbidity and mortality must occur on a locally adapted evidence-based platform but robust local research is lacking in contrast with developed nations.

Countries in SSA operate in an environment of low resources, which has resulted in cancer management largely focusing on those presenting with overt symptomatic disease.[4] [5] The system-level challenges are heterogenous across SSA but factors germane to all countries include limited healthcare financing, inadequate financial protection (universal health coverage), inadequate infrastructure development as well as the need for health systems to manage a dual burden of infectious disease and growing non-communicable diseases.[5–8]

The lack of coordination and fragmented pathways in cancer care at all stages including

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The study interrogated two layers of factors (context and delays) by considering the 'Three Delays' framework.

⇒ We used the Risk of Bias in Non-randomised Studies of Exposures (ROBINS-E) tool to evaluate the quality of studies.

⇒ We reduced heterogeneity by focusing on solid tumours, excluding awareness studies and restricting the timeframe to allow for applicability of findings to the evolving healthcare systems with time.

⇒ The quality of the studies included was largely poor; however, rigorous assessment of risk of bias across seven domains allowed deduction of key study findings that are a useful steppingstone for further investigation.

prevention, symptom awareness, diagnosis, treatment and post-treatment care makes cancer hard to manage in developing nations and ultimately result in high levels of premature mortality.[9] Interventions occur in silos within three distinct groups: (1) across specific cancer types which are prioritised;[10] (2) across prevention, treatment and palliation;[11] (3) across primary, secondary and tertiary healthcare sectors.[12] Additionally, building strong system linkages to coordinate cancer care across primary, secondary and tertiary sectors within country are generally overlooked and this results in critical delays.[9]

Fragmented pathways of care and research priorities are also reflective of the dependence on external international financial donors which tend to support their own specific agendas perpetuating silos of development.[13][14] This approach can be considered reductionist as it fails to consider the system and structural drivers of inequalities in access to diagnosis and treatment.

Evaluation of the unique social, economic, geographic and cultural determinants for late diagnosis and poor treatment outcomes are imperative to provide locally generated evidence. This will ensure the effective implementation of national cancer control programmes.[15][16] These factors are not just context specific (eg, country, region) but also tumour specific. An array of factors including accessibility to care (distance and cost), quality of care, coordination of care across healthcare sectors, education and training, as well as intricate personal and community relationships (values, beliefs, socioeconomic parameters, gender) need to be interpreted in each situation and considered explicitly.

Empirical work has sought to identify the factors influencing cancer diagnosis and treatment delay.[17] However, to our knowledge there have been no attempts to synthesise the available evidence from primary quantitative research undertaken in the SSA context to inform cancer control policies and identify gaps in the current research literature. Gaps would include country settings, tumour types, or at-risk populations which remain under-researched. In addition, robust study designs need to be employed to help compare results between studies and provide further insights as part of the system evaluation.

In this review we used the 'Three Delays' framework to support the synthesis and classification of research studies focusing on barriers to diagnosis and treatment. The Three Delays framework has been used in other health conditions, for example, child and maternal health, emergency medicine however, to date it has not been applied to cancer care delivery.[18][19] The framework considers three contexts and Three Delays. The three contexts are the: patient context (perceptions of disease, barriers to care, cost of illness); provider context (care process quality and outcome evaluation, healthcare workers perceived system barriers); community context (proximity and physical accessibility of services in the community). The Three Delays are seeking care, reaching care and receiving quality care.[20] Delay 1 seeking care: this is the delay in recognising illness and deciding to seek appropriate medical help outside the home. Delay 2 reaching care: this is the delay in reaching an appropriate health facility. Delay 3 receiving quality care: this is the delay in receiving quality care after reaching the health facility. The interconnection in the delays can be seen in figure 1.

The aim of this investigation was to identify common factors influencing diagnostic delays of adult solid tumours and highlight areas that require further study whether that be specific countries, tumour types or settings, in order to help target resources and inform interventions that reduce cancer survivorship disparities globally.
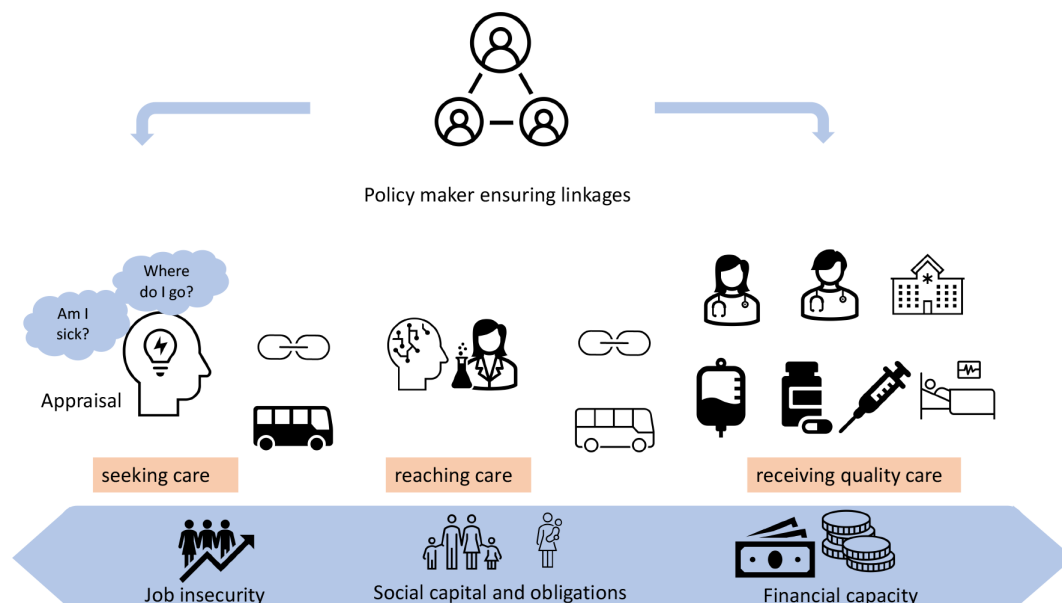
Figure 1 Three Delays framework.
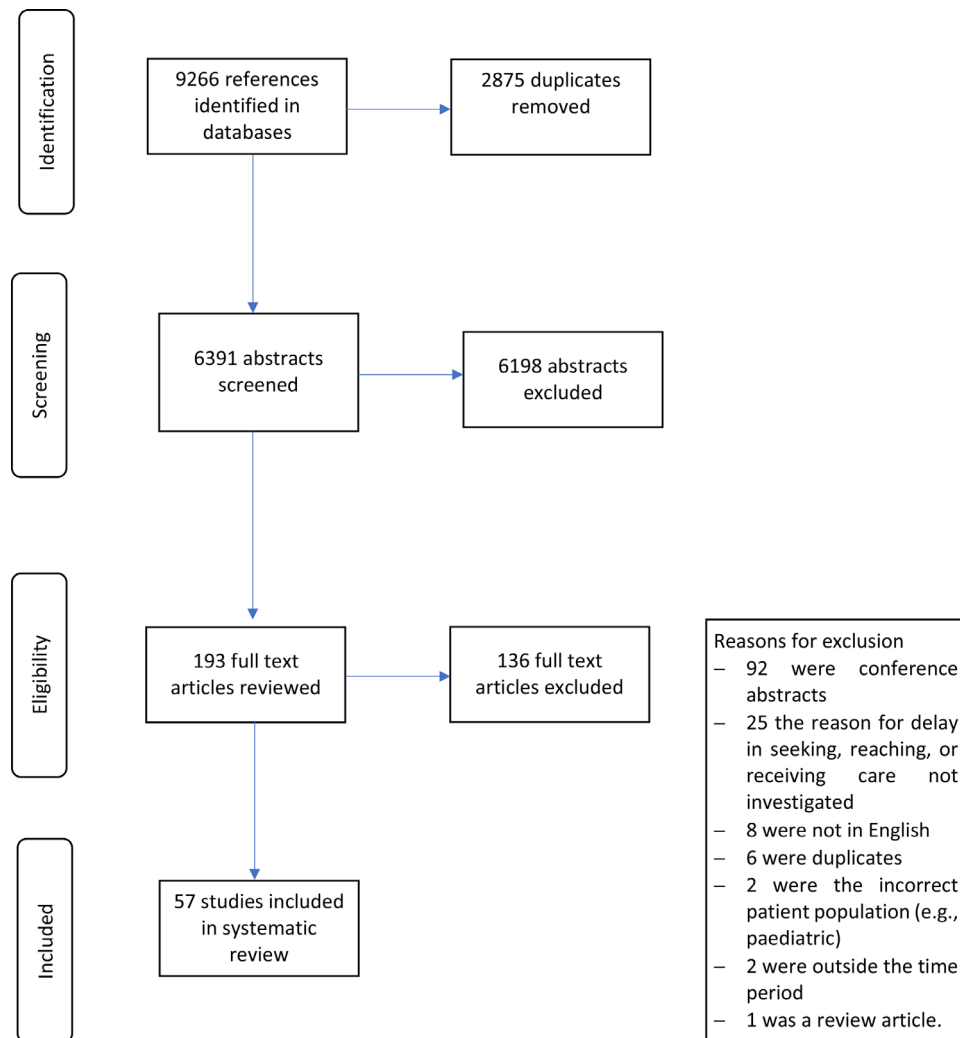
Figure 2 Flowchart of study selection.

METHODS

Study design

We undertook a systematic review and the findings are reported according to the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses. The study selection flowchart diagram is presented in figure 2.

Search strategy

The literature search was conducted on eighth March 2021 in PubMed and Embase for articles published between January 1995 and March 2021. We restricted the timeframe to allow for relevance and applicability of findings to the evolving healthcare systems with time. The full search strategy is in the online supplemental appendix 1

Eligibility criteria

The study included published articles in the English language that focused on solid cancers. The primary research was focused on SSA countries. Types of studies included quantitative (surveys, observational studies) or studies using mixed-methods research methodologies. The quantitative studies had to include patients who had

received a diagnosis of cancer. We excluded studies that included paediatric populations, haematologic malignancies, as well assessments of public perceptions and awareness of cancer since the focus was on patients with a cancer diagnosis and treatment pathways. Haematological malignancies have been excluded because the pathways of referral, detection, management and prognosis are very different compared with solid organ malignancies and would require a separate evaluation.

Study selection

Two reviewers (DCL and MM) screened the abstracts and full-text articles with a third reviewer (AA) to resolve any conflicts. We utilised the systematic review tool Covidence to screen, extract and validate data.[21]

Data abstraction and synthesis

The two primary reviewers extracted and validated the entries together before merging the outputs. Data extracted included year of article publication; country of study; demographic characteristics (age, gender, HIV status, education, marital status, employment, income level); country-level setting; disease subsite; study design;

type of delay investigated, reasons for delay and primary outcomes.

Quality assessment was interrogated with Risk of Bias in Non-randomised Studies of Exposures (ROBINS-E) tool by DCL and AA.[22]

Patient and public involvement
None.

RESULTS
Study characteristics
An initial search identified 6391 articles of which 193 underwent full-text review (figure 2). Fifty-seven studies were included in our final sample and data extracted.[23–78] The full data extraction output is included in the online supplemental appendix 2.

Country and setting profile
The majority of studies were conducted in Nigeria, 15 (26%), Ethiopia, 8 (14%) and South Africa, 7 (12%). Five (9%) were undertaken in Uganda, four (7%) in Kenya, and three (5%) in Rwanda. Four (7%) studies were carried out in more than one country. Only 9% (n=5) of the studies were carried out at national level. Of the remaining studies, two-thirds were conducted at the hospital level (n=38) and a quarter (n=14) being conducted at regional level.

Research design
Two-thirds of included studies used a cross-sectional survey design. The rest of the studies included analysis of patient-level data collected retrospectively (23%) or prospectively (11%). Case–control and Delphi studies represented 4% of studies.

Tumour types
Breast cancer was the most studied tumour type for our research question (53%, n=29) followed by cervix (18%, n=10). About 21% of studies (n=12) evaluated multiple tumour types while there were smaller studies on colorectal cancer (n=2) and Kaposi's sarcoma (n=1). There were no eligible studies on other high burden diseases in SSA such as prostate cancer and oesophageal cancer identified in the literature.

Participant population
Patients identified in a hospital setting were the target population in 48 out of 56 studies. In the other studies, the target populations were patients and clinicians (n=3), clinicians only (n=1), a combination of clinicians, public health opinion leaders and NGOs (n=1), patients in a community setting (n=2) and patients and health facility administrators (n=1).

Assessment of study quality
Fourteen cohort studies met the eligibility for a full assessment. The scores across the domains are illustrated in figure 3. The exposure and outcome characteristics are included in the online supplemental appendix 3. Two cohort studies did not require full interrogation as preliminary assessment of bias by asking the following three questions placed them in the very high-risk category: (1) Did the authors make any attempt to control for confounding? (2) Was the method of measuring exposure inappropriate? and (3) Was the method of measuring the outcome inappropriate? The remaining 40 were surveys. However, all the studies provided valuable insights that we used in the narrative synthesis. A similar finding on data quality from this region has been highlighted before in a contemporary systematic on the routes to diagnosis
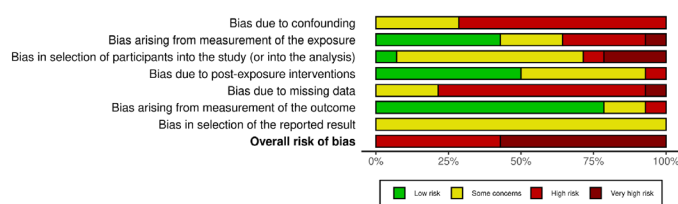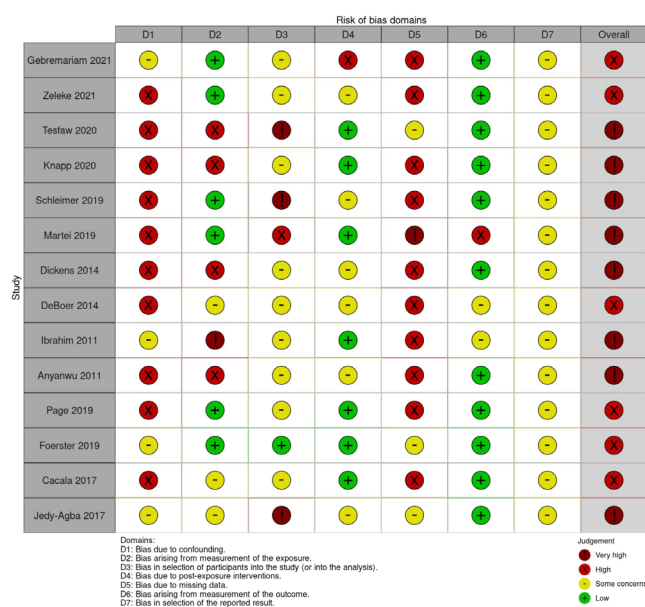

Figure 3 Quality assessment of studies (n=14). McGuinness and Higgins.[86]

of symptomatic cancer in SSA.[79] Figure 3 illustrates the different domains and proportions of bias across the studies. For the studies that were assessed comprehensively all of them had an overall judgement of high or very high risk of bias. In most studies the patient-related confounders (age, marital status and socioeconomic status such as income and education level) were collected as variables but not controlled for appropriately. Health systems factors were poorly accounted for in statistical analysis plans.

Three Delays framework

We synthesised the empirical studies into the Three Delay areas: seeking, reaching and receiving quality cancer care. About 37% (n=21) of the studies investigated all Three Delays while 42% (n=24) focused on 2 delays and 21% (n=12) on 1 delay. Table 1 outlines how the various studies addressed the components of the Three Delays framework.

The reasons of the delays amalgamated from the studies and identified as contributing to each type of systems delay are outlined in table 2. They are further synthesised into economic, psychological, sociocultural, health services and geography subthemes and referenced appropriately in the text. The comprehensive output with outcomes of the data extraction is included as online supplemental appendix 2.

Seeking care

Reasons for delays in seeking care included a lack of awareness about cancer and low health literacy which manifested itself as fears, false perceptions and beliefs and embarrassment about cancer.[26 28 31 32 35 37 38 40 42 42 44 51 55 58 60 64 65 67 70 71 73 77 78] There was also a preference for seeking treatment from traditional or faith-based healers.[27 30 32 35–38 42 44 46 48 49 51 55 57 58 65 70 71 77 78] Participants in the various studies recounted the belief they had not been sick enough or did not have adequate money to justify abandoning their obligations (both financial and social);[26 27 29 31 37 38 42 45 51 52 55 56 58 72 77 78] they rather reassured themselves about the seriousness of symptoms (eg, lumps) as the symptoms did not cause disability or pain in the early stages of disease and that it was self-limiting.[26 31 36–38 42 44 47 51 53 67 73 78] Additionally, not knowing where or how to enter the health system for symptoms before they cause life-threatening conditions contributed to delays in seeking treatment.[31 37 44 46] The unknown costs of managing cancer was also noted to intimidate patients and delay presentation as a result.[26 44]

Reaching care

The physical distance to appropriate care was cited as a major barrier for patients who have to take into consideration transport costs to specialist facilities, accommodation and subsistence costs.[23 27–29 32 33 37 40–42 47 50–52 55 56 60 62 71–73 77 78] Even when transport is made available, they carry the cost of being away from their jobs and families. Other than geographical distance, low levels of cancer care knowledge among primary-level healthcare staff was also a barrier for referral of patients.[31 37 45 70 74 78] This was identified as a source of misdiagnosis and underlay the lack of recognition for the urgency of transferring care to tertiary institutions. In one study, participants had reported that they had been misinformed at the primary level that their condition was incurable.[38]

Receiving quality care

The paucity of infrastructure, equipment, medication and human resources needed for cancer care underpinned the barriers to receiving quality cancer care.[28 62 69] We noted a lack of availability or poor quality diagnostic equipment and treatment facilities were also challenges identified.[58 62 70] Other factors included demotivated and burnt-out staff and the lack of specialist training of staff in cancer.[25 28 31 32 38 56 62] Tensions and mistrust of the system as a whole between the patients and healthcare providers operating in constrained environments were reported as contributing to factors that drove patients to alternate medicine or even simply abandon treatment.[31 47 52] In addition, the lack of availability of essential resources lead to high prices and catastrophic out of pocket expenses for the patients.[23 29 31 32 36 42 47 49 52 55 56 61 62 76 77]

DISCUSSION

The impact of delays in the cancer care pathway on persistent high mortality rates are well recognised. Countries in SSA are called on to accelerate the establishment and implementation of their cancer control plans and it is pertinent to recognise that while respecting the unique aspects of each nation, utilisation of a common knowledge base avoids duplication and allows for prudent efficient use of scarce resources.[2 16] In this regard, results from research using a robust methodological approach provides a foundation for common knowledge that is applicable broadly.[17]

However, our systematic review of studies in SSA investigating the barriers to access to cancer care demonstrates a very limited number of studies despite the importance of this subject area, with heterogeneity in study design which limits their translational impact. The publications we found were clustered to the Northern and West African regions and given the heterogenous factors influencing the SSA region data cannot reliably be extrapolated across the continent. In addition, 70% of the studies focused on breast and cervical cancer with major causes of cancer-related mortality and morbidity such as prostate and oesophageal cancer not addressed which is of major concern. The results highlight the need for a coordinated approach to manage these evidence gaps with no studies addressing the barriers to diagnosis and treatment of cancer identified in 35 of 48 countries in SSA.

The capacity to conduct robust research is increasingly possible across countries in SSA but it requires considerable efforts to coordinate these resources to support a common agenda based on country and regional-level

Table 1 Three Delays framework distribution of studies

First author name	Year	Cancer type	Country	N	Setting	Design	Three Delays
Gebremariam et al[34]	2021	Breast	Ethiopia	223	Regional	Retrospec	C
Zeleke et al[46]	2021	Cervical	Ethiopia	410	Hospital	Retrospec	A
Mapanga et al[31]	2021	Lung	S.Africa	27	Regional	Delphi	A, B, C
Nakaganda et al[29]	2020	Multisite*	Uganda	359	Hospital	Survey	A, B, C
Tesfaw et al[63]	2020	Breast	Ethiopia	426	Regional	Retrospec	A, C
Tesfaw et al[65]	2020	Breast	Ethiopia	371	Regional	Survey	A, C
Reibold et al[25]	2020	Breast	Ethiopia	51	Hospital	Survey	C
Knapp et al[54]	2020	Breast	Nigeria	609	Hospital	Retrospec	A, B
Leng et al[62]	2020	Multisite†	Nigeria	186	Hospital	Survey	A, B, C
Togawa et al[55]	2020	Breast	Namibia Nigeria Uganda Zambia	1518	Hospital	Survey	A,C
Swanson et al[76]	2020	cervical	Uganda	268	Hospital	Survey	C
Foerster et al[40]	2020	Breast	Uganda, Zambia, Namibia, Nigeria	1429	Hospital	Survey	A, B, C
Dereje et al[45]	2020	Cervical	Ethiopia	212	Regional	Survey	A, C
Dereje et al[44]	2020	Cervical	Ethiopia	231	Regional	Survey	A, B
Agodirin et al[78]	2020	Breast	Nigeria	420	Regional	Survey	A, B, C
Martin et al[28]	2019	cancer type not specified	Rwanda	73	National	Survey	C
Page et al[66]	2019	cervical	Kenya	505	Regional	Prospect	A,B
Low et al[43]	2019	Multisite‡	Uganda	100	Hospital	Survey	A, B
Wambalaba et al[69]	2019	Multisite§	Kenya	1048	National	Retrospec	A, C
Grosse Frie et al[57]	2019	Breast	Mali	124	Regional	Survey	A, B, C
Yang et al[41]	2019	Breast	Tanzania	196	Hospital	Survey	B
Schleimer et al[27]	2019	Breast	Rwanda	151	Regional	Retrospec	A, B, C
Foerster et al[61]	2019	Breast	Uganda Nigeria Namibia	1335	Hospital	Prospect	A, B, C
Tapera et al[56]	2019	cervical	Zimbabwe	78	Regional	Survey	A, B, C
Agodirin et al[60]	2019	Breast	Nigeria	237	Regional	Survey	A, B, C
Rayne et al[33]	2019	Breast	S.Africa	252	Hospital	Survey	A, B
Subramanian et al[52]	2019	Breast	Kenya	800	Regional	Survey	A, B, C
Olarewaju et al[42]	2019	breast	Nigeria	275	Hospital	Survey	A, B, C
Ajah et al[30]	2019	Multisite¶	Nigeria	95	Hospital	Survey	A
Martei et al[59]	2019	Multisite**	Botswana	286	Hospital	Retrospec	A
Herbst et al[24]	2018	Colorectal	S.Africa	162	Hospital	Retrospec	C
Anakwenze et al[50]	2018	Multisite††	Botswana	214	Hospital	Survey	A, B
Moodley et al[53]	2018	Breast	S.Africa	201	Hospital	Survey	A, B
Joffe et al[26]	2018	Breast	S.Africa	499	Hospital	Survey	A, B, C
Awofeso et al[70]	2018	Breast, Cervical	Nigeria	105	Hospital	Survey	A, B, C
Bhatia et al[67]	2018	Multisite‡‡	Botswana	214	Hospital	Survey	A,B
Oladeji et al[32]	2017	Multisite§§	Nigeria	218	Hospital	Survey	A, B, C
Jedy-Agba et al[39]	2017	Breast	Nigeria	316	National	Case-control	A, B

Table 1 Continued

First author name	Year	Cancer type	Country	N	Setting	Design	Three Delays
Alatise et al[58]	2017	colorectal	Nigeria	127	Hospital	Survey	A, B, C
Cacala et al[51]	2017	Breast	S.Africa	172	Hospital	Prospect	A, B
Brinton et al[48]	2016	Breast	Ghana	1184	Regional	Survey	A, B
Mlange et al[64]	2016	Cervical	Tanzania	202	Hospital	Survey	A, B
Mwaka et al[73]	2015	Cervical	Uganda	149	Hospital	Survey	A, B
Long et al[47]	2015	Multisite¶¶	Cameroon	220	Hospital	Survey	A, B, C
Pace et al[37]	2015	Breast	Rwanda	144	National	Survey	A, B, C
Tadesse[74]	2015	cervical	Ethiopia	198	Hospital	Survey	B, C
Dickens et al[75]	2014	Breast	S.Africa	1071	Hospital	Retrospec	B
De Boer et al[72]	2014	K.Sarcoma	Uganda	161	Hospital	Retrospec	A, B
Ntirenganya et al[71]	2014	Breast	Rwanda Sierra Leone	6820	National	Survey	A, B
Fasunla et al[49]	2013	Sinonasal	Nigeria	61	Hospital	Survey	A, B, C
Ibrahim et al[68]	2011	cervical	Sudan	197	Hospital	Retrospec	B
Anyanwu et al[23]	2011	breast	Nigeria	275	Hospital	Retrospec	B, C
Otieno et al[35]	2010	Breast	Kenya	166	Hospital	Survey	A, B, C
Ezeome et al[38]	2009	Breast	Nigeria	164	Hospital	Survey	A, B
Clegg-Lamptey et al[77]	2009	breast	Ghana	101	Hospital	Survey	A, B, C
Ukwenya et al[36]	2008	Breast	Nigeria	111	Hospital	Survey	A, B, C

*Cervix, Kaposi's sarcoma, breast, prostate, oesophagus.
†Breast, cervical, head and neck, prostate.
‡KS, cervical cancer, breast cancer, esophageal cancer, head and neck cancer, non-Hodgkin lymphoma, vulvovaginal, prostate, conjunctival squam cell ca, penile, melanoma.
§Cervix, breast, esophagus, prostate, ovary, colon, thyroid, pancreatic, lung, liver.
¶Cervical, ovarian, endometrial, vulva, choriocarcinoma, leiomyosarcoma.
**Cervical, breast, prostate, esophageal, lung, uterine, ovarian, colorectal, head and neck cancers, Kaposi sarcoma.
††Cervical, breast, head and neck, vulvar, aposi sarcoma, endometrial, penile, anal, oesophageal, lymphoma, prostate.
‡‡Cervical, breast, head and neck, vulvar, Kaposi's sarcoma, endometrial, penile, anal, oesophageal, lymphoma, prostate.
§§Uterine cervix, breast, head and neck, prostate, GIT.
¶¶Skin, breast, colorectal, gynecologic, anal; Three Delays codes.
A, seeking care; B, reaching care; C, receiving quality care; K. Sarcom, Kaposi sarcoma; N, sample size; Prospect, prospective; Retrospec, retrospective; S. Africa, South Africa.

priorities.[80 81] Presently, a discordance between research needs and research funding priorities across the continent has been accelerated by the synthetic external agendas in individual countries rather than supporting endogenous solutions driven by those experiencing the problems.[82 83] This is exemplified by our findings which show research is concentrated on a pool of four or five better resourced countries and two main tumour types likely related to the availability of external funding.

Most published data have been obtained through cross-sectional surveys, which detail the prevalence of reasons for delays but fail to account for important cofounding factors and system-level processes to enable the effective problem solving. Nonetheless they still provide a valuable baseline insight that we integrated into a 'Three Delays' model.

The common roots of the reasons for delays at each level of seeking, reaching and receiving quality care as listed in table 2 are first fear (apprehension or mistrust)

and second, a lack of resources (financial, human or infrastructure). Across all delays, cost is a major factor that influences the interval between the stages in the cancer pathway. Out of pocket expenses are high with patients requiring cover for transport, accommodation, diagnostic tests and medicines. A significant number of patients live under the poverty line and it may seem unrealistic for the families to spend on what is perceived to be an incurable disease in the first instance.[84] A recent study demonstrated the threat of catastrophic health expenditure that accompanies a cancer diagnosis even with the basic drugs in low and middle income countries .[85]

In seeking care, fear is compounded by the lack of awareness (knowledge) on the disease, availability of services or how to navigate the pathways to quality healthcare. It can drive patients to rely on familiar systems of alternative medicines (traditional healers, 'Chinese' medicine, faith-based healers). In addition to these challenges taking time off from work or domestic obligations

Table 2 Reasons for Three Delays

Reasons for seeking care delay	Reasons for reaching care delay	Reasons for receiving quality care delay
Psychological		
Belief in witchcraft	Preference for alternative treatment	Defaulting because of side effects of drugs
Denial		Declining treatment
Embarrassment		Fear of wasting doctor's time
Fear of being asked to stop habits for example, smoking		Fear of treatment (eg, mastectomy)
Stigma		Lack of consent
Secrecy		Preference to observe
Putting others needs first		Preference for alternative therapies (herbal, Chinese, acupuncture, food supplements)
Prior bad experience at health centre of hospital		
Preference for care abroad		
Lack of trust in health system		
Fear of doctors, diagnosis, dying, job loss, losing part of body, missing family commitments because of treatment, telling people of illness, treatment		
Sociocultural		
Family and friends' disapproval	Family responsibilities	Communication barriers
Busy schedule	Lack of a caregiver to accompany to facilities	Family commitments
Anticipated long waiting time at clinic	Obligations at home	Language barrier
Preference for prayers and spiritual intervention		No relative to care for them during treatment
Preference for food supplements/organic foods		Patients changing mobile numbers so cannot be contacted for further management
Preference for alternative therapies (herbal, homeopathy, Chinese, acupuncture)		Ignorance on available treatment
No one to look after children		
Low education		
Lack of personal initiative		
Ignorance on how to seek healthcare		
Lack of awareness of symptoms		
Economic		
Impact of taking time off work	Dependence on others for transport	Cancer not priority
Anticipated expense of treatment	Difficulty making appointment or reaching doctor	Failure to come back for follow-up diagnostic or treatment appointments
Transport challenges (eg, cost)	High cost of prediagnostic costs	Failure to find accommodation as outpatients close to treatment centre
Prioritising day to day survival over seeking help	High cost of transport	Financial incapability
Obligations at home	Inability to afford clinic visits	High cost of medicines
No health insurance	Lack of money (for transport)	Paying out of pocket expenses
Financial incapability	Work commitments	Poor nutrition
Geography		
Distance	Distance	
Travelled away from home (out of comfort zone)	Lack of knowledge of estimated distance to nearest service	
Health service		
Lack of cancer awareness programmes and screening	Lack of navigation in primary care	Absence of multidisciplinary team care
	Long investigation time at first contact	Burnout and disinterest of healthcare workers
	Misdiagnosis at lower levels	Diagnostic delay

Continued

Table 2 Continued

Reasons for seeking care delay	Reasons for reaching care delay	Reasons for receiving quality care delay
	Was told by healthcare worker there was no treatment for disease	Chemotherapy stock outs
	Turned away from clinics for arriving late	Few specialists
		High patient volume compared with resources
		Lack of continuity of care by same healthcare workers
		Lack of palliative care and counselling services
		Lack of pathology and screening services
		Lack of smoking cessation clinics
		Lack of specific appointments with specialists
		Unwelcoming, demotivated and uncommitted staff turn patients away
		Long appointments, waiting periods
		Misdiagnosis
		No bed space
		Not healthy enough to continue treatment
		Patients changing mobile numbers so cannot be contacted for further management
		Poorly trained staff
		Power outages
		Unavailability of treatment modality
		Surgeon/operating room unavailability
		Pre-referral diagnosis not communicated
		Poor collaboration among healthcare workers

to attend healthcare appointments is often relegated in terms of priorities due to financial and social implications. Societal expectations also create fear of stigmatism and promote secrecy that hinder free information flow between those seeking it and its custodians.

For reaching care the lack of adequate coordination of services was the dominant theme. Poorly trained staff or lack of support for primary healthcare practitioners delayed referrals to more specialised services and the health system in such a scenario could possibly discourage patients on the curability of the condition. Links and relationships are essential between primary and secondary/tertiary healthcare as most patients will present first to local clinics or health posts. This is particularly important where systems are not electronically linked for results to be easily attainable between practitioners.

To receive quality care, patients need access to a healthcare system with appropriate human resource and infrastructure (diagnostic and treatment). A lack of human resource encompasses both the competence of the workforce for tertiary services as well as the actual low numerical value of specialised knowledgeable staff leading to burnout. Equally a skilled and competent workforce without appropriate infrastructure or sufficient medication and surgical supplies cannot be expected to deliver quality care. Another aspect to consider for receiving

quality care includes patient factors like good nutritional status, financial capacity and social capital to undergo treatment. Acceptance and adherence to treatment are also integral to a successful intervention as investigated by Anyanwu et al.[23]

The findings from our study suggest that reasons for delays are interlinked both at an individual level and population level (figure 1). An individual with vulnerabilities at the seeking-level phase would most likely experience repetitive barriers in reaching care as well as receiving quality care. An underdeveloped health system with poor linkages between primary healthcare and tertiary-level care will inevitably have a large proportion of patients falling through the cracks between phases of care. This could be due to untimely referrals and inability to support diagnostic costs thereby relying on the patient to raise funds.

Limitations

A major limitation in the interpretation and application of the findings of this research output is the quality of the included studies. Recognition of this limitation and application of additional triangulation has assisted us to utilise what is available in this space. Future directions based on our findings would be to conduct more research studies

that will provide quality data for policy formation and effective implementation.

CONCLUSION

To see a reduction in cancer mortality in SSA health systems need to address delays within the cancer pathway from initial presentation and appraisal to completion of treatment and the survivorship pathway. Holistic support for the patient as well as the workforce across the continuum and longitudinally in each phase is important to achieve good outcomes. Cognizance of the multiple barriers presents for individual patients from developing a cancer to its treatment is important for policymakers and experts to build resilient and effective cancer control programmes. With an individual in mind an effective population approach can be achieved. Due to the paucity of organised data in SSA, the starting point of research is often extrapolated from other regions who have different realities. In carrying out this systematic review we intend to provide an organised pool of information that will provide a robust resource for other researchers seeking to conduct studies in SSA.

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