Case Study

The role of primary care practitioners in cancer control in South Africa: a systems-based case study

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Aim

Cancer care has largely been the domain of oncology specialists. With increased awareness of the importance of primary care in the context of universal health coverage, there has been a shift to explore the role of primary care in comprehensive cancer management. This includes health promotion, screening, diagnosing, referral to oncology services, and longitudinal care that includes co-ordination of care, survivorship, and palliative care. This paper focuses on the role of primary care practitioners in health promotion, early detection and care co-ordination. Nurses and doctors who work in primary care are included as primary care practitioners.

Methods

Using a patient vignette narrative tool, the triad of patient empowerment in the form of enhanced health literacy, clinical competence, and system effectiveness, are discussed as the basis for early cancer detection. A complex intervention to improve primary-level cancer care and the implications thereof for the important role of care co-ordination undertaken by primary care practitioners, is also presented.

Findings

For effective patient assessment, primary care practitioners must be trained in screening and diagnostic techniques as part of their clinical competencies as generalists. These competencies include risk identification, counselling skills, expert clinical examination, interpretation of basic x-rays, minor surgical skills, interpreting blood tests, and point-of-care ultrasound. Against a backdrop of ongoing budget constraints, consumables and equipment needed for diagnosis should be readily available and referral pathways for patients and specimens should be clearly defined and resourced.

Conclusions

Primary care practitioners in community-based facilities are well-placed to engage with the psychosociocultural dimensions of care. The SA health system places primary care at the point of closest contact with communities. Efficient care pathways are needed by primary care practitioners to adopt the role of care co-ordinator when patients with suspected or confirmed cancer enter these pathways. When considered alongside the overburdened primary care patient-load and the ever-increasing mix of co-morbidities, the complexity of primary care is appreciated. Understanding the complexities of primary care in the context of cancer control is an important component of a holistic cancer control programme.

Introduction

Cancer is the fourth leading cause of mortality in South Africa, preceded only by cardiovascular disease, infections and violence.[1] According to the Cancer in South Africa 2008-2019 report,[1] cancer mortality accounted for 9.7% of all deaths in the country in 2018, representing a 29.3% increase from 2008. Among women that year, cervical, breast and colorectal cancer were the most prevalent, at 43.5% of all cancer diagnoses. Most prevalent

among men, accounting for 34.9% of all cancer diagnoses, were prostate, colorectal and lung cancers. These mirror global trends in cancer prevalence for men and women.[2]

Despite the relatively high burden of disease presented by cancer, it is estimated that most patients with cancer in low- and middle-income countries (LMICs) experience significant delays in accessing care, specifically in time to presentation, time to diagnosis, and time to treatment.[3] This may be one of the causes of poorer outcomes compared to upper-middle- to high-income countries where these delays tend to be less.[4] In resource-scarce contexts, early detection of cancer has been mooted as an important component of the cancer care pathway that could impact outcomes significantly.[5] Consequently, it is imperative that adequate detection services are provided at the first point of contact between the patient and the health system, the community-based primary care clinic.

Primary care is defined by the World Health Organization (WHO) as health services that "support first-contact, accessible, continuous, comprehensive and coordinated person-focused care".[6(p1)] In the context of cancer care, these principles, especially that of comprehensiveness, become important. However, in many LMICs, significant barriers exist to achieving this care: health literacy levels within a population may be low, resulting in inappropriate health-seeking behaviour; screening or outreach programmes may not have wide reach within communities to find at-risk individuals; access to equipment or services needed for diagnosis may be limited; primary care providers (PCPs) may not be adequately trained or experienced to perform diagnostic procedures; and communication between PCPs, their patients and referral networks may be deficient, resulting in poor care co-ordination.[7] That being said, South Africa has well developed screening policies for the common cancers in women, namely, breast[8] and cervical[9] cancer, with varying rates of implementation success across geographic regions and the socio-economic spectrum. However, this disease-centred approach that focusses on a single screening process, as documented in the separate national government policies on cervical and breast cancers,[8,9] represents a belief that the complex problem of early cancer detection can be adequately addressed using a simple, linear solution. This study argues against a linear approach, proposing that a complex intervention is needed to adequately address the current situation in primary-level cancer care.

This paper focusses on the role of PCPs as members of multi-disciplinary primary care teams, with a specific focus on early detection and care co-ordination. It must be stated that developing staff capacity is one of the building blocks of a resilient health system, alongside robust funding, infrastructural investments, efficient supply chains, and health information and surveillance systems. As seen from Mrs A's story (Box 1), early detection of cancer is potentially enhanced by patient knowledge and awareness, community-based education, proactive risk detection and screening programmes, and efficient diagnostic and referral processes. The discussion that follows unpacks this complexity.

Case description

In the case study profiled here, there are several areas that could potentially have improved the outcome for Mrs A. Delayed presentation to the clinic influenced by her beliefs about the problem, lack of awareness and appraisal of the dangers, and difficulty in accessing the health facility are the most obvious barriers. Added to this, the lack of access to diagnostic radiological services like ultrasound or mammography in the rural primary care clinic and the inability of the primary care staff to do a biopsy, would have further delayed the diagnosis. In her instance, even if referral had been expedited, it would most likely have been too late for curative intervention, but this still highlights the need for efficient referral systems that favour patients needing urgent (rather than only emergency) assessments. Sr C received no communication from the hospital, severely curtailing her ability to engage appropriately with the family or to assist with co-ordinating palliative care for Mrs A.

This case profiles the complexities in delivering effective primary care for early detection and diagnosis of cancer. Patient factors relating to accessibility and health literacy, staff factors relating to workload, knowledge, and skills growth, and systems factors relating to a lack of access to technology and co-ordinated care pathways were identified.

Discussion

Cancer care in South Africa, from a district health perspective, forms part of the non-communicable disease (NCD) domain in the District Health Barometer (DHB).[10] The DHB is published periodically by the Health Systems Trust, collating data on core elements of district health system performance across South Africa, and informing policy and strategy in the national Department of Health. The NCD domain covers cardiovascular diseases, hypertension, diabetes mellitus, chronic obstructive pulmonary diseases, cancer, and mental health. Within this domain, cervical cancer screening coverage is used as a proxy to track progress in cancer care, in pursuit of the achievement of Goal 3.8 of the Sustainable Development Goals (SDGs). This makes sense from a pragmatic perspective, as the screening process is easy to do, needs minimal technology at the point of testing, and can be performed by nurses. Despite this, the overall coverage reported in the DHB (2019-2020) indicated low national coverage of 46.8% (32-57.9%) of the target population, with five provinces falling below this average.[10] Recommendations made in the DHB report include a sharper focus on cervical screening in areas of poor coverage, improving testing for human immunodeficiency virus (HIV) infection, and an appreciation of the complex-

Box 1: Mrs A's story

Mrs A, a 67-year-old woman, presented to her local rural clinic. She had a wound on her breast that had slowly been getting bigger over the previous three months, and was now starting to smell. She did not think it was serious because she had no pain at all. This fact, besides the difficulty of hitch-hiking the 15km to the clinic, and her faith in her home remedies, impacted the time taken to seek care.

She was seen by Sr C, an experienced clinical nurse practitioner, who is also the facility manager. Together with her team of nurses and a once-weekly session by the local general practitioner, Sr C provides comprehensive primary healthcare services to the nearly 15 000 people living in and around the rural town. These services include ante-natal care, family planning and well-baby clinics, acute and emergency care, TB, HIV, mental health and chronic care (mostly diseases of lifestyle and osteoarthritis).

Sr C immediately recognised a potentially malignant lesion and referred Mrs A urgently to the district hospital, which is in a larger town about 25km away. Because it was not an emergency, the earliest appointment was in two weeks' time.

Three months later, Sr C met Mrs A's daughter at a school meeting. The daughter informed her that her mom had died in hospice in the larger town, as there are no palliative care services in their hometown. When admitted, the cancer now confirmed, had spread to her brain, and she remained bed bound. The family was able to visit her only once before her death, due to financial reasons.

ity of pathways when accessing cancer care. Measuring cervical cancer screening as the only indicator of cancer care does not do justice to the overall state of cancer care in the district health system, as cervical screening is markedly different from cancer detection in other common cancers like breast, prostate and colorectal cancers. Additionally, the actual complexity of delivering primary care services, as alluded to in the vignette above, is not addressed and may contribute to the underlying reasons for this poor coverage.

An intervention that sustainably strengthens primary care systems requires attention to the patient, staff, and system factors previously mentioned, all of which are compounded by chronic underfunding. Additionally, an effective strategy would need reconfiguration of the structural components of primary health services to include a community-oriented perspective, deepened appreciation of the psychosociocultural nature of cancer experiences, linkages to care that are responsive to individual needs, and efficient movement and communication along these care pathways when linkages are made. Undoubtedly, this can only be achieved with enhanced health literacy of patients and capacitated staff who are appropriately resourced.

The PCP and health promotion in cancer care

The importance of health literacy has been documented by Harries and colleagues, who explored women's health-seeking behaviour for possible breast cancer symptoms in South Africa.[11] Reasons cited by participants for delayed presentation to a formal health facility were: perceived mild symptoms, stigma, and health service issues like long waiting times. In a separate study, levels of awareness of cancer and related symptoms varied across regions and the rural-urban divide, highlighting the need for context-specific interventions.[12] Low levels of knowledge about cancer in at-risk populations is a significant barrier from a systemic perspective, and mandates that the primary health services and PCPs are equipped and capacitated to provide health-promotion activities in this regard.

The PCPs play an important role as part of the primary care multi-disciplinary team in promoting healthy behaviour and disease prevention through empowering patients by engaging with their health beliefs, enhancing health literacy, and sharing information to facilitate informed decisions and actions.[6] This may be achieved by adopting a community-oriented approach through direct involvement in community outreach programmes, support to community-based organisations in developing patient education interventions, and individual engagements with patients within the consultation. The systematic review by Agide and colleagues of the influence of health-promotion activities on patient behaviour in relation to cancer self-screening, supports the rigorous implementation of these activities.[13] The studies included in their review spanned a broad range of interventions and although a meta-analysis was not possible, individual studies consistently showed significant changes in patient behaviour post intervention. In the context of the current study, the workload of PCPs is saturated with clinical consultations, minimising the opportunities for engagement in health-promotion activities. This reality is not unique to South Africa and has been reported from India as well.[14] One of the real challenges faced by PCPs is the siloed nature of policy-driven health-promotion activities, such as the separate policies advocating for cervical and breast screening.[8,9] This represents a disease-centred approach to health promotion, rather than a people-centred approach that would foreground an at-risk population. Given the stated complexity of primary care, an integrated person-centred, risk-based approach would be a more suitable fit for this context. This would take the form of health-promotion activities that facilitate "connecting with people, connecting through groups, and connecting with self".[15(p1)] It foregrounds the longitudi-

nal relationships that PCPs develop with their patients and communities, while also acknowledging the vulnerability of the PCP to some of the conditions being spoken about and in relation to self-care. In a system where health promotion is often the domain of lay community health workers, the supportive and counselling role of nurses and doctors cannot be underestimated, given the inherent differences that exist in basic understandings of self-care.[16]

Clinical knowledge and skills for early diagnosis in primary care

For PCPs to suspect or diagnose cancer in their context, they need the requisite knowledge, skills, and access to equipment. The process of diagnosis falls within the WHO defined, "Step 2: Clinical evaluation, diagnosis and staging".[7(p8)] In defining the attributes of a PCP who can complete this task, the WHO guideline identifies having, "(an) appropriate index of suspicion, clinical skills and resources"[7(p14)] as core requirements. In a local public health context, the 'index of suspicion' should be informed by the local burden of disease. This should be the first level of intervention aimed at capacitating PCPs in primary level cancer care. In this regard, Benedict and colleagues found that knowledge and practice in relation to prostate cancer, the most common cancer in male patients in a South African context, was inadequate.[17] The principle of knowledge-driven action is central to effective healthcare. The skills that PCPs are required to have to improve early diagnosis relate to physical examination, clinical reasoning, and minor procedures to collect specimens like cervical swabs, fine-needle aspiration, and punch and excision biopsies.[7] These skills require specific training in the processes of identifying appropriate indications, counselling patients and obtaining consent, performing the procedure, and providing safe follow-up care, including the early identification of complications and their management. PCPs must additionally be adept at interpreting radiographic data such as x-rays and ultrasound. A European systematic review suggested that time to diagnosis can be impacted significantly if point-of-care ultrasound (POCUS) is incorporated into the primary care context.[18] POCUS is currently highly topical in South African primary care, with the introduction of more cost-effective mobile devices, and the clear delineation of specific tasks that can be taught and implemented in a relatively short time.[19] While training opportunities within health services are offered for specific activities like cervical smears, training does not exist in South Africa to facilitate comprehensive skills development for the PCP to enact all of these procedures.

Improving cancer care pathways from primary care

In an ideal world, Mrs A would have had a raised level of suspicion for cancer much earlier. Sr C could have asked the visiting doctor to perform an ultrasound-guided biopsy under local anaesthetic while they waited for a mammography appointment. Within two weeks, following histological and radiological confirmation of cancer, Mrs A could have been referred to a tertiary centre. The tertiary centre's main task would be to stage the cancer and develop and implement a curative treatment plan. Sr C would be part of a health information system that would allow her to keep Mrs A's family updated on all these developments, using language that is culturally accessible to them.

The issue of enhanced patient health literacy and staff clinical capacity has already been mentioned. The role of the PCP in co-ordinating care across referral pathways is often neglected. The WHO identifies poor co-ordination as a key barrier to accessing timeous cancer care, and specifically mentions lack of referral pathways, fragmented health services, and poor communication between health facilities and patients' families as modifiable factors.[7] Although the literature has not clearly identified a quantifiable impact for care co-ordination on cancer survival,[19,20] patients and their families have benefitted from structured co-ordination efforts, mostly evidenced by enhanced quality of life.[21,22] In primary care, with its high load of patients with undifferentiated problems, using a generic cancer risk-based,[23,24] rather than disease-specific, approach to developing referral pathways may yield better results and simplify an already complex referral system. A second key intervention would be in the communication domain. It is known that enhanced communication between healthcare professionals (HCPs) and patients improves the patient and family experience of the cancer journey,[21,22] but little can be learnt from published studies of the impact on survival rates of enhanced inter-facility or between-HCP communication due to the low level of research attention this receives.[25] Additionally, technology that facilitates communication between HCPs across the care continuum could enhance the quality of care provided to cancer patients and their families.

Complexity in primary care and early cancer detection

Primary care clinical practice is inherently complex. When one adds the challenge of early cancer detection, the complexity is augmented by multiple factors. This is acknowledged by Rubin and colleagues in a seminal publication in Lancet Oncology in 2015, discussing cancer care in the context of general practice in the United Kingdom.[26] They reported that, in addition to the clinical variety and load that typifies primary care, the expectation is that the cancer load in primary care increases as diagnostic services become more freely available, citing a threefold increase in demand for biomarker testing in primary care when that became available for ovarian cancer. The implication of these findings for the South African context is that simply adding extra services to primary care will add to an already overburdened workload and overstretched budget, which may not result in the desired outcomes.

The clinical complexity of primary care in South Africa is borne out by Mash and colleagues, who described the wide variety of diagnoses seen in primary care across four provinces in the country.[27] They found that NCDs dominate the primary care mortality burden. Despite this, cancer did not feature in the top twenty-five diagnoses made by the primary care facilities they surveyed. When reading this in conjunction with the mortality data discussed earlier, it seems that cancer diagnoses, in primary care at least, are overwhelmed by the myriad of other presentations that PCPs are expected to manage competently. The clinical complexity is exacerbated by the fact that patients presenting to primary care often have undifferentiated or non-specific symptoms not easily classifiable, needing difficult-to-access investigations in upstream facilities. Moodley and colleagues highlighted the need for a systems-level intervention, reporting that, despite seemingly good clinical acumen when presented with hypothetical clinical scenarios, PCPs still need education and support about referral pathways and existing policy.[28]

Early diagnosis is a potential game-changer in cancer epidemiology. While screening programmes are important, data from the UK suggest that, despite strong screening processes in place, most cancers are diagnosed based on symptom presentation,[29] implying that the patient is an active player in early cancer detection. Proactive, knowledgeable patients presenting to capacitated PCPs working within a supportive care pathway result in efficient referrals for definitive care.[29] However, when cancer diagnoses are suspected or made in South Africa, the referral pathways present an emerging challenge.[5] A scoping review found that late presentation, delayed recognition and diagnosis, and delayed referral all featured significantly in patients' cancer journeys,[30] highlighting the need for effective co-ordination across care pathways.

This brings to the fore the PCP's role as a care co-ordinator across the different levels of care. This co-ordination role is seen as one of the six core competencies required of family physicians in South Africa who are district-level specialists and regarded as clinical leaders in the district healthcare system.[31] To date, family physicians are still sparsely distributed across the SA primary care platform, and care co-ordination suffers as a result.[32] For those PCPs (nurses and medical officers) who work at the coalface of primary care service delivery, being tasked with the additional role of care co-ordinator is an unrealistic expectation.

The triad of clinical competence, system effectiveness, and patient empowerment in the form of enhanced health literacy, could form the basis for a complex intervention to improve primary-level cancer care. A comprehensive cancer intervention in primary care should include health worker capacity-building (resources, skills, and support), system strengthening that facilitates early diagnosis and referral of cancer patients, together with proactive care co-ordination across the levels of care, and community health promotion. This is a necessarily complex approach, which is understandable given the inherent complexity of primary care as the first point of interface between communities and health services. Skivington and colleagues described a 'complex intervention[33] as an intervention that targets different groups of people, behaviours or contexts. It is considered complex because many groups of people and activities need to be targeted in order to achieve the desired outcome across multiple platforms. Recognising the complex nature of a cancer care intervention in primary care acknowledges that there is no single solution with a linear cause-effect observation, but rather that a multi-faceted approach needs to be employed, cognisant of the multiple confounding variables that characterise social spaces.

Lessons learnt

There are three clearly defined areas in which PCPs could engage to strengthen primary care cancer systems: (1) by contributing to enhanced health literacy and empowerment for patients and communities using a community-orientated primary care (COPC) approach; (2) enhancing the capacity of PCPs, as members of the primary care and community-based multi-disciplinary team, for early diagnosis of cancer; and (3) being active in care co-ordination within care pathways that facilitate efficient referral and communication. The complexity of primary care cannot be addressed by simple, linear solutions. A suitably complex intervention with well-defined outcomes could make inroads into this challenge.

Enhancing health literacy and patient empowerment

Current job descriptions for PCPs are almost entirely focussed on providing curative services for symptomatic patients, with health-promotion activities being the remit of lay community health workers. With the current workload, PCPs are not able to engage meaningfully in health-promotion activities. For PCPs to become more deeply involved in health-promotion activities, this study proposes that three conditions need to be met:

1. Health promotion must be incorporated into their job descriptions with full support from line managers.
2. They would need training to be able to facilitate learning for 'people, groups and self'.[20] This would include models of consultation that facilitate individual cancer risk identification, and facilitating group learning within communities.
3. Integrated health-promotion policies that focus on at-risk cohorts, rather than disease-specific policies, need to be developed and disseminated. This would need wide collaboration across disciplines and levels of national and provincial departments of health.

Enhancing early diagnoses in primary care

In the context of the high workload and relative diagnostic resource scarcity in primary care in SA, it is often more expedient to refer a patient to a higher level of care rather than to attempt a diagnostic procedure. The implication of this reality for a delayed diagnosis of cancer is not yet known. An integrated approach to ensuring that PCPs have the requisite knowledge and skills to facilitate early cancer diagnoses would entail:

1. PCPs having knowledge of the cancer burden of disease as it relates to morbidity and mortality, with specific reference to at-risk cohorts within the population being served. This curriculum should include knowledge of specific cancers as it relates to the early diagnostic processes, which would represent a radical divergence from current undergraduate teaching on cancer that focusses largely on the tertiary interventions for advanced cancer (staging and curative interventions). Higher educational institutions should be called upon to develop and implement these training modules.
2. PCPs developing, maintaining and enhancing physical examination skills as a key source of clinical data gathering, given the relative paucity of diagnostic technology in primary care.
3. PCPs developing, maintaining and enhancing their ability to use and interpret radiological services like x-rays and point-of-care ultrasound.
4. Training in minor surgical procedures being offered to PCPs as appropriate to their professional scope of practice, within a well-defined referral pathway. This should include methods to protect the integrity of specimens in resource-constrained contexts.

Improving cancer care co-ordination of pathways from primary care

A considered approach to mapping the care co-ordinator role of PCPs would include:

1. The PCP working within a defined care pathway, with clear referral criteria and mechanisms for rapid transit within clinical governance policies.
2. Developing risk-based guidelines for implementation within these care pathways that are patient rather than disease-centric. These guidelines should take into consideration the relative lack of resources in primary care to make definitive diagnoses in many instances.
3. Developing digital communication platforms for healthcare workers. There are several potential solutions already in use across the country and, in the context of cancer care, these should be purposively leveraged to effect impact.

Conclusion

This paper proposes a comprehensive and complex intervention for PCPs that could plausibly have a significant impact on early detection of cancers, resulting in improved outcomes. It aligns with the WHO's integrated people-centred care approach, illustrated in Figure 1, which seeks to humanise health systems.[34] In South Africa, the implementation of the National Health Insurance Act presents an interesting opportunity for this radical re-engineering of primary healthcare.[35]

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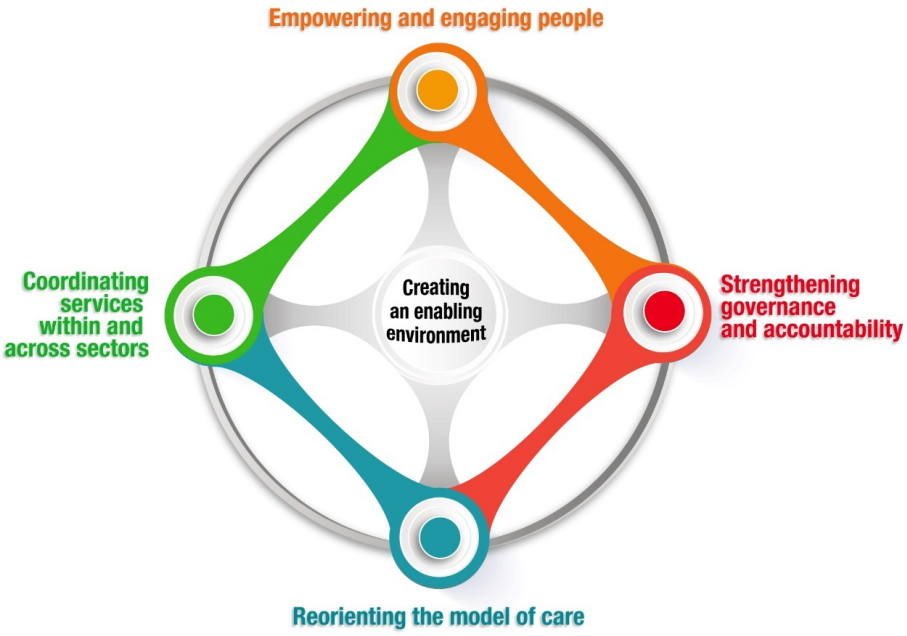
Figure 1. Components of the WHO integrated person-centred care approach



Source: WHO, 2024.[34]

Abbreviations

Abbreviation	Description
COPC	community-orientated primary care
DHB	District Health Barometer
HCP	healthcare professional
HIV	human immunodeficiency virus
LMICs	low- and middle-income countries
NCDs	non-communicable diseases
PCP	primary care practitioner
POCUS	point-of-care ultrasound
SDGs	Sustainable Development Goals
UHC	universal health coverage
WHO	World Health Organization

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