

Providers' Understanding of Cancer Aetiology and Supportive Features for Indigenous Palliative Cancer Care Service Provision in Kenya

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Abstract

Background: Palliative care is a fundamental component of providing people-centred health services to cancer patients. However, the primary pillars of indigenous palliative care such as provider understanding of cancer, its aetiology, and features are undocumented.

Objective: We sought to understand Traditional Health Providers (THPs) understanding of cancer aetiology, and the functional features that support indigenous palliative cancer care service provision in Kenya.

Method: The study used a mixed methods cross-sectional design. A semi-structured questionnaire was administered to 193 THPs, who self-reported to manage cancer patients. The findings were enriched and validated through member checking in 6 focus group discussions and five journey mapping in-depth interviews.

Results: Despite diversity in culture and experience among the indigenous providers in Kenya, their description of cancer aetiology and their management practices and primary goal were similar. Cancer was consistently described as a deadly life-deforming disease by 61.1% of THPs ($n = 118/193$) and attributed to chemicals and toxins in the body 41.5% ($n = 80$). The indigenous palliative-care system was reported to be characterized by five tiered levels of care, diversity in expertise and experience, shared and consultative process (60%) and family involvement in medical decision (59.5%). Herbal regimen (60.1%) was found to be the cornerstone of informal palliative care blended with nutrition management 78.2% ($n = 151$), lifestyle changes 63.7% ($n = 123$) and counseling services 55.9% ($n = 108$). Payments for service were arbitrarily made in cash or in kind.

Conclusion: The features of indigenous palliative care services are informed by the providers' distinctive cultural terms and descriptions of cancer and cancer aetiology. Shared and consultative protocols, regimen exchange, referral to cascaded care, and caregiver involvement were all important palliative-care clues to saving and enhancing lives. The features provide context for development of indigenous palliative care framework, engagement of policy makers, and promotion of culturally-inclusive indigenous palliative care model for adoption.

Keywords

Traditional health provider, cancer and its aetiology, supportive features, Kenya

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Introduction

Cancer is a major public health and economic issue globally and the leading cause of death worldwide.^{1,2} An estimated 18.1 million cases and 9.6 million cancer deaths were recorded globally in 2018.^{3,4} Half of the new cancer cases and cancer deaths in the world occur in Asia. Northern America is second in terms of new cases (13%, 2.4 million), and fourth for cancer deaths (7%, .7 million). Close to one fourth of all new cases globally (4.2 million) and one fifth of deaths (1.9 million) occur in Europe.⁵⁻⁷ In Africa, cancer is the fifth leading cause of death, but is projected to rise the fastest compared to the rest of the world⁵⁻⁸. In Kenya, cancer is the third leading cause of death with a mortality of 7% per annum, which is expected to double by 2025 due to unhealthy lifestyle modification.^{9,10} Annually, over 39000 new cases are diagnosed while 27000 persons die of cancer. The most common cancers in Kenya are breast, cervical, prostate, esophageal, and colorectal.^{2,10,11} In Kenya, the prevention, treatment, and control of cancer faces various challenges, including availability, accessibility, affordability and acceptability.^{9,10,12} Perhaps due to these barriers, numerous cancer patients seek informal indigenous medicines and palliative care.^{2,10,13}

Palliative care is defined as a health care approach that improves the quality of life of patients and their families affected by a life-threatening illness.^{5,13} This is through the prevention and relief of suffering by means of early identification, rigorous assessment and alleviation of pain and other physical, psychosocial, and spiritual health issues.^{5,13} According to the World Health Organization (WHO), palliative care should be provided through person-centered and integrated health services that pay special attention to the specific needs and preferences of individuals.¹³⁻¹⁵ However, the potential role of Kenya's indigenous palliative regimen in cancer management is undocumented.^{9,13,16,17}

Accordingly, data on principles behind the practice of African indigenous palliative care may illustrate how contrary it is to conventional western health care assumptions and practice which typify a one-size-fits-all approach.¹⁸⁻²⁰ Additionally, the cultural ambience consistently mirrors the professional behaviour and values, and needs to be supportive to the wishes of the people affected by cancer along the various stages of their illness. Only when providers' values embody the core ideals of the care recipient can the practice transform to a patient-centered model.^{21,22} In Kenya, indigenous providers popularly known as Traditional Health Practitioners (THPs) are governed by values and principles as well as the guidelines and ethos set out by THPs, professional groups and regulatory bodies. Examining these values, ethos and features will enhance the understanding of indigenous

palliative care and provide the basis for development of service models.^{19,20} Furthermore, Research defining provider understanding of cancer and its aetiology, scope of practice, caregiving models and value of regimen will help improve medical practice and guide the adoption of best practices to broader context.²³⁻²⁵

Material and Methods

Design and Study Setting

A mixed methods cross-sectional study design was used to describe the structural and functional features that support the Kenyan indigenous palliative care system as well as the providers' knowledge of cancer and its etiology. Mixed methods research was adopted because it offers a more complete analysis and greater validity of issues.²⁶ Seven agro-ecological sites of Kenya were selected for this study, with a preference for the major towns of Mombasa, Nairobi, Kisumu, Nakuru, Kericho, Nyeri, Thika, Machakos, Kakamega, Kisii, Eldoret, and Meru, where prominent indigenous practitioners are active, as well as rural areas for renowned practitioners.

Sampling and Sampling Procedure

A sampling frame was created from the roster of THPs registered with the Kenya Ministry of Tourism, Wildlife and Heritage, and the National THP Association (NA-THEPA). This list was enlarged through snowballing and referral, in which THPs shared their networks of other known THPs who might be willing to take part in the research. Screening questions (screener) was administered to potential participants to identify qualified THPs to take part in the research. Registered THPs who handled cancer patients, had been in practice for more than a year, were willing to participate in the research and consented were considered for inclusion. Providers who who did not wish to participate or reported to have lost a loved one, 12 months prior to the study were excluded but debriefed appropriately before being discharged. The inclusion criteria were fulfilled by 201 THPs.

Data Collection Procedure

Data collection was undertaken from October to November of 2019. Two hundred and one THPs who met the inclusion criteria were consented and interviewed at their convenience by trained research assistants. For THPs with multiple satellite clinics in different towns, interviews were scheduled based on the THPs rotational availability at the chosen clinic. THPs from all the

ecological regions of Kenya were visited, with the exception of the North Eastern region due to insecurity. A THP in charge of the outlet authorized access to the outlet, and to primary providers. Participants were informed that their participation in the study was voluntary, were assured of preservation of their anonymity, and confidentiality of data. All consenting persons signed prior informed consent forms. On the day of the interview, a semi-structured provider questionnaire was administered to the primary THP responsible for diagnosis and prescription of palliative regimen. The questionnaire captured respondent's profile, understanding of cancer and cancer aetiology, outlet features, care practices, partnership approaches, and financing.

The quantitative data was cleaned, coded, and analyzed using Statistical Package for Social Science (SPSS) version 22. Findings were verified through member checking during qualitative interviews. Qualitative interviews were conducted to understand the context of practice, validate and gain a deeper understanding of themes deduced from the questionnaire. Six focus group discussions (FGDs) were undertaken. Each FGD ran for an average of 75 minutes and comprised of THPs selected via cluster sampling. The participants were clustered according to region of practice and ethnicity. Five THPs deemed to have the best practices were selected to participate in the in-depth-interviews (IDI), and each was interviewed individually for no more than 1 hour. The criteria for 'best practices' consisted of: operation from structured outlets defined as a stand-alone partitioned clinic separate from homestead; use of referral materials; patient records and information; documented management procedures; patient perception and satisfaction; and research participation. Co-creation was optimized during the qualitative studies to situate the THPs palliative concept and process and real time simulation.

Ethical Approval

The Institutional Research and Ethics Committee of Kenyatta National Hospital- University of Nairobi (KNH-UoN) approved the study (KNH ERC/A/319), while the National Commission for Science, Technology and Innovation (NACOSTI), Kenya, permitted the protocol (NACOSTI/P/18/41 197/24 208). The study was guided by three regulations. First, the study relied on Article 31.1 and Article 24 1 of the United Nations Declaration on the rights of peoples and intellectual property law in regards to intellectual property rights.^{27,28} Secondly, Kenya Law N° 33 of 2016 on protection of traditional knowledge and cultural expressions act.²⁹ Third and most important, human subject research ethics. Consenting respondents did not receive any direct benefits in exchange for the information, but they were reimbursed for highway transportation costs. Research etiquette, study aims and procedures, and consenting processes were covered during training of the research team.

Data Analysis

The research analysis had two fronts. Quantitative data was analyzed using SPSSv22. Descriptive analysis was undertaken to capture trends and proportions in the data distribution with focus on THP profile, cancer knowledge, outlet dynamics and management practice. Qualitative data was analyzed concurrently using thematic content and discourse analysis techniques to search for important words, texts, nuances, patterns and themes in the data. The dual process allowed competing explanations to account for the observed results.³⁰ Content analysis allows for interpretation of textual data from the FGD through the process of coding and identification of themes³¹ Data were categorized and sub-categorized, coded, and themes identified. The qualitative themes and quantitative figures were supported with excerpts and direct quotes from the data.

Results

Demographic Characteristics of the Respondent

From the 201 interviews administered, 8 had incomplete returns and thus results were computed from the remaining 193 participants. All but three participants interviewed were of Kenyan descent. Respondents were of diverse ethnic background predominated by Agikuyu 23.3% (n = 45), Abaluyia 17.0% (n = 33), Kalenjin 15.0% (n = 29), Luo 10.3% (n = 20), and Ameru/Aembu 8.2% (n = 16). Of the 193 respondents, 91.2% (n = 176) were married, 89.1% (n = 172) were Christian and 75.1% (n = 145) were male. The median age was 57.55 ± 12.93 years, and most (92.2%; n = 178) THPs were above the age of 40. Close to half the THPs (48.7%; n = 94) had been providing indigenous care for more than 21 years. Seventy-five respondents (38.8%) had primary education, while nearly a third (n = 60) had a secondary education. In addition to being care providers, 67.9% (n = 225) of them reported farming as their main source of income, while 17.9% (n = 56) and 15.2% (n = 50) additionally ran a business and had formal employment, respectively [Table 1].

THP's perspective on Cancer and its Etiology

Cancer was described as a serious terminal or life-deforming disease by most (61.1%; n = 118) of the respondents [Table 2]. One THP reported '*For many Kenyans, cancer is an incurable condition marked by torture, toil and death. But to us (THPs), cancer is manageable and curable provided it is diagnosed early.*' For 26.4% (n = 51) of the THPs, cancer is a lifestyle condition induced by toxic environmental conditions. Further 2.6% (n = 5) and 9.8% (n = 19) said cancer was hereditary and pathogenic disease managed by natural products. Based on that line of reasoning, Kenyan communities describe, tag cancer with unique names and conditions. The Luo tagged cancer '*Dhola/Adhola*' - a leprosy-like

Table 1. Respondent's Demographics Characteristics.

Characteristics	Proportion (%) n = 193
Gender	
Male	145 (75.1)
Female	48 (24.9)
Age	
<40 years	15 (7.8)
41-49 years	36 (18.7)
50-59 years	50 (25.9)
60-69 years	57 (29.5)
>70 years	35 (18.1)
Marital status	
Married	176 (91.2)
Single/separated/divorced	8 (4.1)
Widowed	9 (4.7)
Education	
None	24 (12.4)
Primary	75 (38.9)
Secondary	60 (31.1)
Tertiary	34 (17.6)
Religion	
Christian	172 (89.1)
Muslim	11 (5.7)
Traditionalist	10 (5.2)
Main source of income	
Business	56 (17.9)
Employment	50 (15.2)
Farming	225 (67.9)
Years in services	
<5 years	17 (8.8)
6-10 years	22 (11.4)
11-15 years	26 (13.5)
16-20 years	34 (17.6)
>21 years	94 (48.7)

condition, or *'Abiera/bunda'* - a disease of the colon that causes great discomfort. Abagusii call it *'Omuaga'* meaning something brought by the wind. The Nandi call it *'Mogongiot'* to mean a condition that forms in the body and harms it. In Kamba, it is called *'Kivivya/Muvivya'* meaning a tumor that selects and kills specific body cells and parts. The Abaluyia call it *'Ingwasi'* meaning a degenerative disease within the body that manifests due to chemicals weakening the body. The Teso call it *'Shokhoro'* - a disease that enters and colonizes the body or body system. For the Ameru/Aembu and Mijikenda it is an untreatable disease/condition named *'Mkoje'* and *'karonda cha rika'* respectively. It is referred to as *'enayiengi'* meaning tumor or surgical condition by the Maasai community while Marakwet/Turgen/Keiyo call it *'siryani/seryan'* or *'lubaniat'* to mean toiling and dilapidating condition. Finally, the Agikuyu refer to cancer as *'ironda cia ndiira'*, a non-healing condition that colonizes the system.

The respondents contended that cancer causes, condition and side effects are philosophical in nature and warrant to be addressed philosophically. In reflecting on causes, 41.5% (n = 80) posited that cancer was triggered by chemicals and toxins in the body. According to the respondents the chemicals are derived from fruits and vegetables and from unhealthy ecology, contraceptives, processed foods and remnants of chemicals. This was affirmed during FGD, where discussants agreed that the history of cancer in the family and unhealthy lifestyle increases the risk and exposure to cancer. A verbatim quote from one THP encapsulated this finding well, *'the food we eat particularly Sukuma wiki and the processed food expose people to cancers, more so, the young people.'* Thirty-six respondents (18.7%) attributed the rise of cancer to unbalanced diet, while 16.6% (n = 32) adduced environmental conditions were to blame. Others attributed cancer to

Table 2. Cancer Description, Cause and Treatment.

Characteristics	Proportion (%) n = 193
Definition of cancer	
Deforming/degenerative/terminal disease	118 (61.1)
Hereditary diseases	5 (2.6)
Lifestyle/environmental/toxicity disease	51 (26.4)
Pathogenic condition cured by herbs	19 (9.8)
Cause of cancer	
Chemicals and toxins in the body	80 (41.5)
Environmental issues	32 (16.6)
Genetics- family history	11 (5.7)
Pathogens like bacteria, virus or parasite	15 (7.8)
Unbalanced diet and poor feeding habits	36 (18.7)
Unknown auto immune causes	19 (9.8)
Cancer curability	
No	9 (4.7)
Yes	184 (95.3)

Table 3. Types of Outlets, Workforce and Patients' Load.

Outlet, Workforce and Number of patients	Proportion (%)	
	Yes	No
Diagnosis approach applied		
Rely on presented patient's clinical records	121 (62.7)	72 (37.3)
Herbalist personal experience	76 (39.4)	117 (60.6)
Rely on patient's verbatim history	69 (35.8)	124 (64.2)
Medical diagnostic tests results	45 (23.3)	148 (76.7)
General presentation of new patients		
Severely ill	139 (72)	
Moderately ill	43 (22.3)	
Mildly ill	11 (5.7)	
Operational outlet		
Home practice with no clinic structure	39 (20.2)	
Home practice with specific clinic structure	39 (20.2)	
Clinic in town area	67 (34.7)	
Mobile without a clinic	48 (24.9)	
No. of staff		
None (self)	57 (29.5)	
1-3	113 (58.5)	
4-6	17 (8.8)	
>7	6 (3.3)	
Routine program		
Await and services patient in clinic	145 (75.1)	
Mobile	48 (24.9)	
Average no. of patients per day		
<5	76 (39.4)	
5-10	83 (43)	
11-15	21 (10.9)	
>16	13 (6.7)	

unknown autoimmune causes (9.8%; n = 19), pathogens such as virus (7.8%; n = 15), and genetics (5.7%; n = 11).

All but 4.7% (n = 9) of respondents believe that cancer is manageable and curable. When asked whether cancer is curable, one THP said, *'for us in informal health care, cancer is curable if presented early or the patient lives a quality life through the holistic treatment approaches, and provided the patient believes and follows the regimen guidelines.'* Another THP stated, *'divine hand is very important in our processes. Belief in God and trusting in your own capability and power of your regimen to defeat the condition are the central tenets through which herbalists derive and maintain a credence that their regimen will cure and manage a cancer condition.'*

Outlet Operational Supportive Features

THPs operate from various service provision points but not all are structured or stationary. The outlets ranged from a clinic in town centres 34.7% (n = 67), mobile outlets 24.9% (n = 48), clinics at home 20.2% (n = 39), and home practice without a clinic 20.2% (n = 39) [Table 3]. Five clinics have both inpatient and outpatient services with filing systems, diagnostic centers,

admission rooms and referral mechanisms. In addition, 70.5% (n = 136) of the 193 THPs had a workforce who supported them to offer services: 58.5% (n = 113) had one to three personnel, 8.8% (n = 17) had four to six staff, while 3.3% (n = 6) had more than seven employees. The personnel were conventionally trained health workers such as nurses, clinical officers, laboratory technicians, records officers and nutritionists. Ordinarily, 75.1% (n = 145) of the THPs attended to walk-in clients presenting at the outlets. On average, THPs attended to nine patients per day, three of whom were cancer patients. According to the providers, 72% (n = 139) of the patients presented were in a severely ill state, while 22.3% (n = 43) and 5.7% (n = 11) were moderately and mildly ill, respectively.

Outsourcing, Partnership and Consultative Supportive Features

Close to 60% (n = 115) involved and consulted other experts in the management of cancer patients. For example, 53.1% (n = 60) consulted health practitioners and laboratory specialists, 29.2% (n = 33) consulted hospitals for confirmation of diagnosis, 14.2% (n = 16) consulted other THPs

Table 4. Skills, Consultation and Combining Herbal With Conventional Medicine.

Skill Acquisition Methods	Yes (%)	No (%)
Observing family/friend members	61 (31.6)	132 (68.4)
Self-driven	71 (36.8)	122 (63.2)
Divine gift from family historical healing	92 (47.7)	101 (52.3)
Academic training	39 (20.2)	154 (79.8)
Apprenticeship	137 (71)	56 (29)
Use of reference materials for your work	115 (59.6)	78 (40.4)
Nurturing and training young people	143 (74.1)	50 (25.9)
Outsourcing and consultation	Frequency	Percent
Health practitioners and lab specialists for consultation	60	53.1
Hospital for testing, checkups and treatment	33	29.2
Other THPs	16	14.2
Both THPs and medical practitioners	4	3.5
Perceptions on combining medication	Frequency	Percent
Approves combining	73	37.8
Does not approve combining	116	60.1
Not sure	4	2.1
Forms of supportive therapies	Yes	No
Counselling	108 (55.9)	85 (44.1)
Lifestyle changes	123 (63.7)	70 (36.3)
Nutrition management	151 (78.2)	42 (21.8)
Massage therapies	55 (28.5)	138 (71.5)
Spiritual	46 (23.8)	147 (76.2)

while 3.5% (n = 4) consulted both THPs and medical practitioners [Table 4]. The key services sought from conventional centers included medical tests and screening, medical imaging, vital signs assessment, diagnostic confirmation and staging of cancer, purchase of drugs and referral. Cross partnership with other THPs was informed by expertise, specialization, availability of herbal ingredients and unique regimen preparation skills. The unique regimens included Chinese medicine, nutritional and dietary services. According to one female THP, partnership with other experts provides a platform for outsourcing, exchange of ideas, synergy, encouragement and assurance. She said: *'we are living in a dynamic and technologically sound society where skills and techniques are mushrooming every day. We learn new ideas and approaches of preparing and dispensing medicine in workshops, seminars and society meetings but we also know the strength and capacity of one another. Therefore, we refer patients, exchange, and borrow materials and expertise.'*

More than half of the THPs (60.1%; n = 116) did not approve the combination of traditional and conventional modalities [Table 4]. According to the THPs, mixing of complementary regimen with conventional medicine prevents detection of the regimen that works and may intoxicate the patient. As recorded by one THP *'it is difficult to tell whether our patients are interchangeably using conventional drugs with our regimen, but we advise them against mixing. We advocate for adherence to one line of medication for good*

success rate and caution on the adverse effects of mixing.' Majority (92.2%; n = 178) of the herbalists compliment their herbal regimen with other forms of therapies. The highly recommended modalities are nutrition management 78.2% (n = 151), lifestyle changes 63.7% (n = 123) and counseling 56% (n = 108). Two others of less degree were massage therapies 28.5% (n = 55) and spiritual nourishment 23.8% (n = 46) [Table 4]. In the words of one elderly female THP of Christian affiliation, *'dieting and lifestyle changes are good for patient satisfaction and healing. You need to tell the patient and the caregiver to be aware of what they need to eat and not eat. They need to know a good menu and why.'*

Cancer Caregiving Supportive Structures

Sixty percent of the THPs (n = 115) opined that the best caregivers are family members - a proposition that resonated with qualitative findings [Table 5]. According to one discussant *'the nuclear family support is paramount particularly from the spouse, children and secondarily the siblings or in-laws. In addition to understanding the patient and his/her circumstance, these core people can provide good nursing care. The neighbours, peers, colleagues at work and church may assist to provide moral, financial and logistical support.'* The other THPs recommended herbalists and conventional practitioners 15.5% (n = 30), anybody with mercy and patience 9.3% (n = 18), herbalist and family 7.8% (n = 15), medical practitioners 4.1% (n = 8) and a

Table 5. Cancer Caregiving Support Structures.

Caregivers	Frequency	Percent
Anybody with mercy and patience	18	9.3
Family members	115	59.6
Family members and convectional practitioners	7	3.6
Herbalist and convectional practitioners	30	15.5
Herbalist and family	15	7.8
Medical practitioners	8	4.1
Total	193	100.0

combination of family members and conventional practitioners 3.6% (n = 7).

Mechanism of Compensation for Services

The average cost per session and summative cost for indigenous palliative cancer care was Ksh 3561 and Ksh 29 066 (26.88 and 219.37) respectively. However, the concept of compensation is relative among THPs. For 21.8% (n = 42) of respondents, in-kind compensation in the form of goods (animals, cereals), and relationship was sound and sufficient. While 17.6% (n = 34), said a token of appreciation starting from Ksh 100 to 1000 (.75 to 7.5) was sufficient. The summative palliative regimen cost ranged from Ksh 500 to Ksh 200000 (3.77 to 1509.50). Group discussions yielded that the compensation in the THP field is characterized by non-standardized and unregulated direct, indirect and non-financial packages. To THPs, the field is more of a volunteerism and a calling than a money-making enterprise. A caption by one THP summed up this: *'my primary aim is to assist a client to recover then it is their responsibility to see how to compensate me thereafter. For example, some bring good gifts such as cows, land and cash while others develop bonds and become good family friends.'*

Discussion

Four themes are discussed in this discussion: The viewpoint of THP's on the causes of cancer, operationally helpful aspects, features that facilitate outsourcing, partnerships, and consultancy, as well as payment methods for services.

THP's Perspective on Cancer and its Etiology

A variety of key quality of life and longevity terminologies and strategies important in indigenous cancer palliative care were uncovered. The unique names and descriptions of cancer and its aetiology in Kenyan dialects resonate with aspects of Russell's theory of descriptions which accounts for the meaningfulness of definite descriptions and linguistic semantics,³² and suggests that disease aetiology is crucial in

palliative care services. For instance, cancer is described as a deadly terminal and life-deforming disease and the terminologies have informed unique naming. The linguistic proposition embodies community or people's emotions, perceptions, experiences, memories, observations, theories and actions with respect to cancer. Accordingly, the physiology, condition manifestation, behavioural pattern, cues to action, misconceptions on prognosis and survival, and consequences, are critical not only in cancer description and aetiology but also its management. The principles resonate with Kenya's multilingual basis of naming systems that appropriates names based on the subjects' manifestations and characteristics. The naming system is well documented and elaborated.³³

The causes of cancer were varied, but predominantly attributed to chemicals and toxic effects derived from vegetables, contraceptives and processed foods. The results suggest that environmental factors are strongly linked to cancer causal beliefs in the informal health care setting. Subsequently, nutrition features prominently in indigenous palliation of cancer symptoms. Unhealthy lifestyle, genetic conditions and unknown auto immune causes were other alleged causes. Our results are consistent with the belief that illness representations and manifestation, specifically the causal belief component, are influenced by family history of cancer and exposure.^{34,35} The results insinuate a conceptual influence of environmental and unknown autoimmune roots in the study participants' perception and understanding of cancer cause. However, detailed research synthesis would validate these perspectives and theories. Informal health practitioners' reason that cancer is manageable and curable provided it is diagnosed early and the patient has the required mental stamina. The practitioner proposition was buoyed by 443 of their patients who upon interview professed that faith in God and overcoming fear and anxiety reinvigorates a patient and empowers them to defeat cancer.¹⁹ Late diagnosis is however a serious challenge in informal health care and could be hampered by stigma arising from cultural interpretations of the origin and description of cancer. This phenomenon is also well documented in the formal health sector^{36,37} suggesting that early and correct diagnosis is a cross-cutting unmet cancer care need.

Outlet Operational Supportive Features

Several outlets operated by THPs from a wide range of locations in Kenya were examined. Characterization of THP service outlets and their scope of operation identified five classes of indigenous health providers: (a) THPs offering mobile services, (b) THPs with stationary service points offering basic health services, (c) THPs offering basic health services in stationary outlets and maintaining patient records, (d) THPs outlets with outpatient and inpatient services, and (e) THPs outlets with laboratory services in addition to outpatient and inpatient services. Similar to conventional medicine, THPs have levels of care. However, they are tiered by scope and workload, patient flow, staffing levels and working situation, rather than the primary, secondary, tertiary or quaternary conventional care levels. Most of the THPs were domiciled in clinics in commercial towns, or home-steads, but a few were mobile. Majority of the clinics provided outpatient services, while a few advanced clinics offered inpatient and outpatient services. Additionally, the scope of the clinic and number of staff varied. The average number of staff was three, but advanced clinics had more than seven members of staff of different cadres. For example, one clinic had the THP as the principal provider supported by clinical officers, nurses, a nutritionist and a laboratory technician. Just like other service providers, THPs receive and attend to walk-in clients at the service points. Generally, most of the patients presented themselves when they were severely or moderately ill suggesting that patients see indigenous services as a final point of care. The finding suggests that patients may have accepted that further medical treatment does not provide holistic cure and hence elect to redefine hope, maintain a good quality of life, and enrich their emotional and spiritual life from intermittent THP services. This is supported by herbalists' practices that advance for healthy life-style modifications such as massage, exercise and spiritual nourishment.¹⁹ For these patients and their families, the holistic nature of care provided within the community indigenous setting epitomizes the ideal patient-family-provider care circuit at end-of-life,¹⁹ and therefore resonates with cultural ways in which disease and death are dealt with.³⁸

Outsourcing, Partnership and Consultative Supportive Features

Outsourcing and consulting were important components of the informal health care system. Similar results have been reported in South Africa.³⁹ Nkosia and Sibiyi acknowledged the importance of consultation and underpinned cooperation and linkage as critical pathways in diagnosis, referral, and improvement of patient management and treatment outcomes. In our study, outsourcing and consultation were widely practiced by the THPs, but to different degrees. The value and importance of outsourcing

and consultation were well pronounced by interviewed patients who held that referral was central to patient-THP-conventional practitioner linkage.¹⁹ This cross consultation is informed by expertise and specialization, adequacy of drugs and unique herbal regimen preparation skills. The result suggests that the influence and role of other people and institutions from within and outside the informal sector is of critical importance in indigenous palliative care in Kenya. For this reason, interdisciplinary and intra-disciplinary opportunities may be exploited as the means of sharing essential information among patients, caregivers, THPs, health workers, and policy makers. The study also revealed that referral was a principal cue to action in indigenous cancer palliative care. The referral system relied on diagnosis and counseling needs, skills of the service providers, condition of the patients, and more importantly, the availability of a specific regimen for certain cancers. THPs were not just aware of, but practiced a rich consultation and referral system similar to conventional health care systems. The consultation and referrals when structured, would fast-track and coordinate support activities such as where to confirm diagnosis and source healthy nutrition foods, treatments models and emerging patient coping strategies, and provide a platform to share and ventilate emerging cancer uncertainties.

Cancer Caregiver Support Structures

Members of the nuclear family were selected as the best cancer caregiver for pseudo-surrogacy situations, interconnectedness and treatment adherence. This finding agrees with available literature that informal caregivers are usually family members or close relatives.^{40,41} The roles of the caregiver included nursing the patient, managing medication, updating the THP on patient condition, and booking revisits when necessary. These roles are well documented in available studies to include helping patients with personal needs, shopping, transport, household chores, and medication.^{40,41} There is however a need to undertake a study characterizing the traits necessary for effective caregiving in THP palliative care.

Mechanism of Compensation for Services

For many THPs, saving lives and healing is the primary motivation and not material gain. The service compensation is however characterized by non-standardized and unregulated direct and indirect packages. For many rural THPs, in-kind compensation is sufficient but monetary package is vital for urban providers. As documented in the patient's study, affordability remains a major challenge while seeking THPs service in urban centres.¹⁹ Consultation fees are unstandardized and unregulated, providing a good opportunity for policy makers and regulators to populate guidelines on THPs consultation fee.

Strengths and Limitations

The current study had the following strengths: (1) large and diverse sample size and (2) an explanatory sequential design, that quantitative data collection and analysis occurred first with findings validated in qualitative data collection and analysis exercise. The referral sampling component may have triggered the Hawthorne effect phenomenon of being aware of being studied, and necessitated similar palliative performance by the THPs. However, the three-tier quantitative large sample size surveys of patient, practitioner and ethno-medicine completed by qualitative member checking countered this phenomenon.

Conclusion

The features of indigenous palliative care services are informed by the providers' distinctive cultural terms and descriptions of cancer and cancer aetiology. Despite Kenyan communities being multiethnic, the palliative care beliefs, values and practices of THPs are similar, and based on shared cultural descriptions and perspectives. Skills and experience diversity, cascaded levels of care, vertical and horizontal integration are key features for the informal palliative-care system. Shared interdisciplinary and intra-disciplinary cues to saving and improving lives entail consultation, partnership, regimen outsourcing, caregiver involvement and referral.

These findings have implications on several levels. Firstly, the identified features and opportunities such as the shared values, diversity of skills, and vertical and horizontal integration provide context for the ideation and development of an indigenous palliative care outlet framework. Secondly, the tiered categories of care, regimen outsourcing, and caregiver involvement highlight that the cooperation and synergy that exists between various service providers and communities can be built upon to include policy makers, and serve as important connections upon which future programs can be built. Thirdly, the resultant fabric blended by social behavioral and interpersonal communication techniques, may make Kenyans indigenous palliative care an integral health prevention, promotion, restoration and curative component that can be adopted globally by countries seeking culturally-inclusive models.

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Authors' Contribution

The authors have contributed significantly for this manuscript. S.K.C., conceptualized the idea, sourced for funds, implemented

the methodology, processed the write up, and analyzed the data. K.L., D.N., P.K., J.M. and W.N., contributed equally in the project write up and editing, design implementation, data collection, supervision and provided technical and critical revision and review of the reports.

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Data Availability Statement

The data that support the findings of this study are available from the corresponding author.

Supplemental Material

Supplemental material for this article is available online.

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