Using Cancer Survivor Narratives in Newspapers to Assess Cancer Health Literacy and Implementation of National Policies on Cancer Prevention, Treatment and Management in Kenya

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BACKGROUND TO THE STUDY

- Cancer is the 3rd leading cause of death in Kenya after infectious and cardiovascular diseases (MoH, 2017).
- In 2012 there was an estimated 37,000 new cancer cases and 28,500 cancer deaths in Kenya (MoH, 2017), an increase from an estimated annual incidence of 28,000 cases and mortality of over 22,000 reported in the National Cancer Control Strategy 2011-2016 (MoH, 2011).
- According to Globocan 2018 (https://gco.iarc.fr/today/data/factsheets/populations), Kenya recorded 47887 new cancer cases and 32987 cancer deaths annually.
- The new cases comprised 19199 males and 28688 females.
- The top 5 most frequent cancers were breast, cervix uteri, oesophagus, prostate, colorectum (MoH, 2018).
With evident low levels of cancer health literacy, the need for attention to increasing knowledge levels is urgent with the mass media playing a critical role.

The *Daily Nation*, a publication of the Nation Media Group, is the leading newspaper in Kenya with a readership of 4,379,400 per day (Elliot, 2015).
METHODOLOGY

- The *Cancer Warrior Story Series* was published in the *Daily Nation*, one of the leading newspapers in Kenya, upon voluntary participation of cancer survivors.

- There was an invitation at the beginning and end of each story to any cancer survivor who was willing to share their experience to do so using a given email address.

- The *Cancer Warrior Story Series* was purposively sampled because it was the only continuous series of cancer survivor narratives carried in a national Kenyan newspaper.

- These articles were obtained from the database of the *Daily Nation*. 
The Cancer Warrior Series featured 11 cancer survivors.

Data was collected and analysed using qualitative content analysis: the systematic reduction of content, analysed with special attention to the context in which it was created, to identify themes and extract meaningful interpretations of the data (Roller & Lavrakas, 2015).

Relevant newspaper articles were retrieved from the database of the Daily Nation, a coding frame was constructed to capture features of each article relevant to the research aims, each article was systematically coded and the data presented in key themes.

The series ran for 4 months: August 2018- December 2018.

The stories were published as follows: 1 story in August, 2 in September, 4 in October, and 2 in both November and December.
The key findings were compared with relevant guidelines contained in national policies prepared by the Ministry of Health (MoH) in Kenya and studies on promotion of health literacy.

These policy documents included: National Cervical Cancer Prevention Program Strategic Plan 2012-2015 (MoH, 2012); National Guidelines for Prevention and Management of Cervical, Breast and Prostate Cancers (MoH, 2012); the National Guidelines for Cancer Management in Kenya (MoH, 2013); National Palliative Care Guidelines (MoH, 2013); National Cancer Control Strategy 2017-2022 (MoH, 2017); Kenya Health Act 2017 (GoK, 2017); the National Cancer Screening Guidelines (MoH, 2018) and the Kenya National Cancer Treatment Protocols (MoH, 2019).
FINDINGS AND DISCUSSION

The key findings were discussed under the following themes:

a) Demographic factors
b) Use of photos, plain language and explanation of technical terms
c) Detecting early signs and seeking diagnosis and treatment
d) Seeking a second opinion
e) Communicating the results of cancer diagnosis
f) Shared decision making
g) Supportive care for cancer patients: palliative and nutritional care
h) Coping strategies
The gender and ages of the cancer survivors are important as they enable readers to assess their own vulnerability to specific cancers.

The articles featured 4 male and 7 female cancer survivors.

8 articles indicated the ages of the cancer survivors: 4 were over forty years while the other 4 were below forty.
10 narratives had photos.

The photos in each narrative had captions explaining details such as the name and age of the cancer survivor, the type of cancer they were suffering from, the date of diagnosis, stage of treatment and recovery, the effects of cancer treatment and their attitude towards life.

The photos were taken in different settings, including in hospitals during treatment sessions.

The photos can promote cancer health literacy and authenticity as the readers can associate what they have read with what they can see.

Photos also help fight stigma as readers can see the cancer warriors who confidently share their experiences.
All the 11 narrators used plain language to describe their cancer experiences. Their explanation of the early signs, their diagnosis and treatment were all explained in a language an average newspaper reader could understand. Plain language is linguistically and culturally appropriate to enhance comprehension of messages on cancer among the majority of Kenyans who speak English as a second language (Simmons et al., 2017).
USE OF PHOTOS, PLAIN LANGUAGE AND EXPLANATION OF TECHNICAL TERMS contd

- 4 narrators indicated that they did not understand technical terms associated with cancer during diagnosis, including: *a fine needle assessment, biopsy, and colostomy*.

- All the narrators showed an understanding of the cancer they were suffering from and the treatment procedures they had undergone as they used technical terms associated with those cancers appropriately.
The articles had further explanations of technical terms such as *multiple myeloma, positron emission tomography (PET scan)* and *prognosis*, as they cited authoritative sources such as the *Mayo Clinic*.

The information provided by the narrators and the explanations of technical terms by the writers of the articles were meant to promote cancer health literacy among readers.
DETECTING SIGNS AND SEEKING DIAGNOSIS AND TREATMENT

- 2 narrators took over 4 years from the time they experienced the first signs of cancer to when they visited hospitals for diagnosis and treatment.
- 4 narrators who took less than 2 years from when they experienced the first signs of cancer to when they were diagnosed and started treatment had been declared cancer free.
- 3 narrators later diagnosed with breast cancer had lumps that were not painful in the beginning and went to hospital only when they started experiencing pain, after a minimum of 2 years.
- 1 narrator did not experience any signs until she underwent a routine test for employment and diagnosed with cervical cancer.
- The National Cervical Cancer Prevention Program (MoH, 2012), acknowledges that implementation of the national cervical cancer screening program is low and haphazard: it is run in a few selected sites and in disjointed projects.
DETECTING SIGNS AND SEEKING DIAGNOSIS AND TREATMENT contd

- A narrator had a painless lump in the stomach for 4 years and was later diagnosed with colon cancer.

- The length of time between detecting the first signs and going to the hospital for diagnosis and starting treatment may determine the extent of the spread of the disease, the kind of treatment required and treatment outcomes.

- Data from Kenyatta National Hospital, the leading national and referral hospital in Kenya, shows that between 2014 and 2016, approximately 64% of cancer patients were diagnosed at stage III or IV, when treatment for cure is difficult to achieve (MoH, 2018).

- Integration of prevention, screening and early detection interventions into other health programs (MoH, 2017) may not have been effectively implemented.
4 of the cancer survivors had been treated for other diseases despite presenting with signs of cancer.

The National Cancer Treatment Protocols (MoH, 2019) observes that there is evidence that patients with cancer-related symptoms are delayed in health facilities and given inappropriate treatment before onward referral.
SEEKING A SECOND OPINION

- 8 of the cancer survivors sought the opinions of other doctors on the diagnosis of cancer and the most effective form of treatment.
- 6 cancer survivors were referred by the doctors they consulted to other doctors for their opinion on diagnosis and the most effective form of treatment.
- 4 of the cancer survivors had been misdiagnosed with other diseases.
- Misdiagnoses prolong a patient’s physical, emotional and financial pain; exposing them to the risk of the cancer spreading further therefore requiring longer and complicated treatment processes as well as negatively influencing treatment outcomes.
COMMUNICATING THE RESULTS OF CANCER DIAGNOSIS

- With the exception of 2, there was no counselling for the other 9 cancer survivors before or after diagnosis with cancer.
- There was no established procedure of communicating the results of cancer diagnosis.
- Only 1 narrator had been told by her oncologist to go with her mother before she could be given the results of diagnosis.
- The cancer survivors were shocked by the news that they had cancer which was at advanced stages and this could have triggered other health problems.
- Communicating the results of cancer diagnosis without counselling contravenes the Kenya National Cancer Treatment Protocols (MoH, 2019) and the Kenya Health Act (GoK, 2017).
Since all the narrators did not have adequate cancer health literacy to participate in making decisions on their cancer treatment, they mainly relied on the oncologists for guidance.

Among the 2 narrators who underwent colostomy, 1 explained that it was done without her consent as it was an emergency while the other said that though her oncologist had explained to her that she was to undergo colostomy, she thought it was a minor surgery.

The 2 were devastated when they woke up and saw the bags.

Healthcare workers in these 2 cases contravened the guideline that patients are entitled to all information about their diagnosis, prognosis, treatment options and costs (MoH, 2013).

1 narrator ruled out radiotherapy when he was told that it destroyed both good and bad cells.
All the narrators said they received financial and emotional support from their families and friends; 8 reported being supported by other cancer patients; 2 were supported by colleagues and 1 by her church leader and church members.

Only 1 reported receiving palliative care from the hospital she was treated in.

1 of the narrators explained that she had been living with HIV for 19 years, had suffered from three types of cancer: cervical, colon and rectal; she had gone through depression; attempted suicide; she had lost her husband, two children and her job, but she did not report receiving palliative care services.

Though palliative care is a fundamental health service and right incorporated in the Kenya Health Act (2017), according to WHO (WPCA,2014), less than 10% of patients who require palliative care in the country do access it.
The National Palliative Care Guidelines 2013 (MoH, 2013) states that healthcare workers should not just focus on preventing avoidable deaths but also avoidable suffering.

The guidelines state that patients and their families shall access holistic palliative care to meet their physical, psychosocial and spiritual needs within their cultural context (MoH, 2013).

Further, MoH (2013) adds that palliative care has a role in patient and community education for prevention messaging, presenting early for treatment, supporting treatment and helping patients cope with the side effects of treatment and in end-of-life care.

By not being given palliative care services, the patients and their families and carers may have missed information on non-pharmacological measures of pain relief, symptom control, nutrition support, infection and prevention control, care and carers and psychosocial care (MoH, 2013).
The National Guidelines for Cancer Management (MoH, 2013) observe that nutritional support of patients with cancer should be an integral part of cancer treatment.

The guidelines further indicate that nutritional care should be in the management plan and started in the initial health assessment or on admission to prevent or correct nutritional deficiencies, minimize weight loss and severity of treatment side effects, and support healing, among others (MoH, 2013).

However, none of the narrators reported receiving information on nutritional care.
COPING STRATEGIES

- 7 of the cancer survivors (5 female and 2 male) indicated that they were in support groups.
- 1 cancer survivor was introduced to a nurse who specialized with ostomates and she taught her a lot about colostomy including cleaning and disposing off colostomy bags.
- The nurse also introduced her to 5 other ostomates and they formed an organization called *Stoma World Kenya* in 2012 which had grown in membership to over 300 and supported members in buying colostomy bags.
- 1 narrator was in a support group of patients, doctors and caregivers and they visited cancer patients, created awareness on cancer, connected and shared.
- 6 cancer warriors (3 male and 3 female) reported deriving their hope of recovery from increasing their faith in God.
3 cancer warriors reported resorting to various activities including singing, meditation and exercise such as swimming.

2 cancer warriors were involved in cancer advocacy and awareness using their support groups.

The other coping strategies practiced by 1 cancer warrior each were: sharing one’s cancer experience with family and friends; giving inspirational talks; writing a book about his cancer journey and using social media to create awareness on cancer.

1 cancer warrior was in an association of cancer survivors that advocated for insurance packages for cancer treatment.
CONCLUSION

- Based on the positive attitude of all the narrators towards recovery from cancer, the narratives were likely to be effective in instilling a similar attitude among newspaper readers.

- The narrators did not detect the signs of cancer early, they delayed in going to hospital for diagnosis and treatment and were not equipped to meaningfully participate in making decisions on their treatment, an indication that cancer health literacy may be very low in Kenya.

- Guidelines on promoting prevention, early detection and screening; communicating the results of cancer diagnosis; palliative care; and treatment protocols had not been adequately implemented.

- Though the narratives lacked information on the risk factors, nutrition and exercise in the management of cancer, and available insurance covers in cancer treatment, they could be useful in promoting readers’ knowledge, motivation and competences to access, understand, appraise, and apply information on cancer in order to make appropriate decisions (Best et al., 2017).