

Prognostic Awareness, Preferences for Prognostic Information, and Health-related Quality of Life Among Advanced Cancer Patients in Kenya

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Abstract

Background

Little is known about prognostic awareness and preferences for prognostic information among patients with advanced cancer in Kenya. This study aims to fill that gap.

Methods

Outcome variables included a measure of prognostic awareness and preferences for prognostic information. Logistic regressions examined the associations between these variables and patient characteristics including age, years of education, socioeconomic status, and symptom burden.

Results

A substantial proportion of patients (36%) were unaware of their prognosis and most (69%) did not want to receive additional prognostic information. Patients with greater preferences for receiving prognostic information were older, more educated, of lower socioeconomic status, and reported less symptom burden.

Conclusion

The high levels of unawareness and preferences against prognostic information provide a challenge for efforts to increase shared decision-making and patient autonomy among historically disenfranchised populations. Greater efforts to educate patients on the value of prognostic awareness should be encouraged.

BACKGROUND

Cancer is the second-leading cause of non-communicable disease mortality in Kenya, the country of focus for this effort. Trends reveal the incidence of cancer increased 45% in recent years, from 37,000 new cases in 2012 to 47,8878 new cases in 2018 [1]. No information exists regarding prognostic awareness or prognostic information preferences among patients with advanced cancer in Kenya. Drawing on evidence from other African countries, unawareness is likely to be high and there may be little interest in receiving prognostic information [2, 3].

Prognostic awareness, defined as the awareness of disease incurability and shortened life expectancy [4], has been associated with more end-of-life discussions [5], better patient-centric care [6, 7], earlier palliative support, fewer unwanted resuscitations [8], and increased shared decision-making [9]. Despite

these benefits, prognostic awareness among patients with advanced cancer in many developing countries, including many in Africa, is low [3] [10].

Based on evidence from literature, we hypothesized that greater prognostic awareness and greater preferences for prognostic information would be associated with younger age [11, 12], having higher education [13, 14], higher income [11, 15], and higher symptom burden [16, 17]. Our findings are expected to inform the extent of prognostic awareness among advanced cancer patients in Kenya and who would most benefit from efforts to increase awareness.

METHODS

Study Aims

We first examined prognostic awareness and preferences for prognostic information among patients with advanced cancer treated at a single cancer centre in Kenya. Second, we investigated the relationships between these outcomes of interests and select correlates.

Study Settings

Data was collected as part of the Asian and African Patient Perspectives Regarding Oncology Awareness, Care, and Health (APPROACH) study, a multi-country cross-sectional study examining advanced cancer patients. Data from the Kenya site was collected between October 2021 and February 2022 at the Moi Teaching and Referral Hospital (MTRH), Eldoret, a level 6 hospital offering specialized oncological and palliative services with a catchment area of 24 million residents in Western Kenya, Eastern Uganda, and South Sudan.

Study Participants

A convenience sample of 207 patients were recruited from the outpatient medical oncology and palliative care departments and inpatient medical and surgical wards at the MTRH through face-to-face interviews. Eligible participants were (1) ≥ 21 years old; (2) diagnosed with Stage IV solid cancer; and (3) able to understand English and (4) who sought treatment at MTRH during the study period. Patients were excluded if they were unaware of their cancer diagnosis, were cognitively impaired or lacked the capacity to complete the survey (as observed by the interviewers or accompanying family caregivers). Ethics approval was obtained from the National University Singapore-Institutional Review Board (NUS-IRB LB-15-319) and the Moi Institutional Research and Ethics Committee (IREC/2021/27). Trained interviewers obtained written informed consent from all participants prior to the survey.

Survey Development

The survey questionnaire was developed as part of the larger APPROACH study with consultations from oncologists and research faculty at participating Centres.

Measures

Prognostic Awareness: Participants were asked: “Do you know the current stage (i.e., severity) of your cancer?”. “Early stage (Stage I, II, or III)” and “don’t know” responses were categorized as “unaware of prognosis” while “Advanced cancer (Stage IV)” responses were categorized as “aware of prognosis”.

Patient Preferences for Prognostic Information: Patient preferences for prognostic information were examined using the question “Would you like to know how long you are likely to live under various treatment options?” “Yes, in general terms”, and “Yes, in general/specific terms” responses were categorized as “wanting to receive prognostic information while “No” and “Not sure” were categorized as “Do not want/not sure of receiving prognostic information.

Patient characteristics: Patient age was taken from patient medical records; all other variables were based on self-report. Patients were asked to report their years of education and socioeconomic status (0: low income, 1: lower middle class, 2: upper middle class). Symptom burden was assessed using questions adapted from the Functional Assessment of Chronic Illness Therapy - Palliative Care (FACIT-Pal) (Version 4) [18]. Examples of these symptoms include pain, shortness of breath, and unintentional weight loss. The symptoms were scored on a 5-point Likert scale ranging from “0: not at all” to “4: very much”. Scores were then summed, with greater total scores indicating higher symptom burden.

Statistical Analysis

Patient characteristics were summarized with mean and standard deviations (SD) for continuous variables and numbers and percentages for categorical variables.

The associations between prognostic awareness and patient characteristics were assessed using a logistic regression. The dependent variable was prognostic awareness (0=unaware, 1=aware) while the independent variables included age, years of education, socioeconomic status, and symptom burden.

A second logistic regression was used to examine the associations between preferences for prognostic information and the same set of independent variables. The dependent variable was defined as preference for prognostic information (0=no, do not want to know or not sure; 1=yes, want to know prognostic information). All analyses were conducted using Stata version 15.1.

RESULTS

Patient Characteristics

A total of 207 patients completed the survey. Sample characteristics are reported in **Table 1**. On average, patients were 55 (SD=15.40) years old and had 8.50 (SD=4.58) years of education. Most were female (57%), married (76%), and lower- or lower middle-income class (63%). Most learned of their cancer 1 to 3 years ago (53%). Patients reported a mean symptom burden score of 12.91 (SD=7.08) (out of 40), indicating that patients in Kenya generally did not suffer from significant symptom burden. (Table 1).

Prognostic Awareness

Roughly one third of patients (36%) remain unaware of their prognosis. None of the associations tested were statistically significant (Table 2).

Preferences for Prognostic Information

In total, 33% of patients stated yes, that they preferred to receive prognostic information as opposed to stating 'no' or being unsure. Contrary to our hypotheses, logit regressions indicated that patients who were older ($\beta = 0.04$; CI: 0.02; 0.06, $p < 0.05$), lower socioeconomic status ($\beta = -0.82$; CI: -1.30; -0.35, $p = 0.01$) and lower symptom burden ($\beta = -0.06$, CI: -0.11; -0.01, $p < 0.05$) were more likely to want prognostic information. Supporting our hypothesis, patients who reported higher education preferred receiving more prognostic information ($\beta = 0.17$; CI: 0.07; 0.26, $p < 0.05$) (Table 3).

DISCUSSION

The primary aim of this study was to examine the prevalence of prognostic awareness and prognostic information preferences among advanced cancer patients in Kenya. The associations between these outcomes and various patient characteristics were also investigated. Roughly a third of patients (36%) reported being prognostically unaware (defined in our study as knowledge of their current stage (i.e., severity) of their cancer). Findings from another study among patients in Africa also revealed high levels of unawareness [3], suggesting that the issue may be systemic. Though our study did not investigate the causes of unawareness, some research has underlined the role of existing paternalistic medical frameworks where providers tend not to include patients as decision-makers [19, 20]. However, our results reveal that the majority of patients in our sample preferred not to receive prognostic information, revealing that patient factors are also at play.

To further our understanding of factors that influence prognostic awareness, we examined the relationship between awareness and preferences for prognostic information with observable characteristics of patients. Consistent with other literature, we found that patients with higher education preferred more prognostic information [14]. These findings are consistent with the notion that more educated individuals tend to have better health literacy.

We also found that two generally disenfranchised groups were more interested to receive prognostic information. This included older adults and those who reported lower socioeconomic status. Older adults tend to have more emotional stability and be more accepting of their situation [21], they may therefore feel more comfortable asking for and receiving prognostic information [22]. Although the differences by socio-economic status were less clear, it may be that lower-income individuals are more motivated to understand their illness trajectory so they have a better sense of the financial consequences, which may disproportionately impact their households [23]. Lastly, we found that patients with lower symptom burden were more open to receiving prognostic information, perhaps because they (wrongly) think they are more likely to receive good news.

Strengths and Limitations

The strength of this study lay in its examination of patient prognostic awareness and preferences for receiving prognostic information in a country in Africa (Kenya) where little information currently exists. However, it should be noted that our results were conducted in a single site and on a specific illness (i.e., advanced cancer) and therefore may not be generalizable. However, they are generally consistent with the limited research on the topic in African countries. We also did not identify the reasons behind the low levels of prognostic awareness and patient preferences for receiving prognostic information. This should be an area of future study.

Conclusion

Despite these limitations, our results highlighted the substantial level of prognostic unawareness and little interest in receiving such information. Given the necessity of prognostic awareness for achieving patient-centred care and meeting patient preferences [24], efforts to increase awareness among patients with advanced cancer in Kenya should be a priority, especially among patient subgroups that have been historically disenfranchised. This is likely best achieved through a multifactorial approach that includes greater emphasis on 1) public health campaigns on the value of informed decision-making, 2) provider training in health communication [25], 3) advanced care plans, and 4) protocols that necessitate informed consent [26].

Abbreviations

APPROACH: Asian and African Patient Perspectives Regarding Oncology Awareness, Care, and Health; FACIT-Pal: Functional Assessment of Chronic Illness Therapy - Palliative Care; MTRH: Moi Teaching and Referral Hospital; NUS-IRB: National University Singapore-Institutional Review Board; SD: Standard Deviation

Declarations

The FACIT and all related works are owned and copyrighted by, and the intellectual property of David Cella, Ph.D. Permission for use of the FACT/FACIT system of questionnaire is obtained by contacting information@facit.org.

Ethics Approval and consent to participate

Ethics approval was obtained from the National University Singapore-Institutional Review Board (NUS-IRB LB-15-319) and the Moi Institutional Research and Ethics Committee (IREC/2021/27). Informed consent was obtained from all individual participants included in the study. All methods were carried out in accordance with relevant guidelines and regulations.

Consent for publication

Not applicable.

Availability of data and materials

Not available.

Competing Interests

The authors have no relevant financial or non-financial interests to disclose.

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Authors' Contributions

Hussein Elias: Writing – Review & Editing; Supervision; Project administration; Funding acquisition.

Semra Ozdemir: Writing – Original Draft; Writing – Review & Editing; Formal analysis; Supervision.

Joann Bairavi – Project administration; Writing – Review & Editing.

Emmah Achieng: Writing – Review & Editing.

Eric Andrew Finkelstein: Writing – Review & Editing; Supervision; Project administration; Funding acquisition.

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Tables

Table 1. Patient Characteristics	
Dependent Variables	
Prognostic Awareness	
Aware	133 (64%)
Unaware	74 (36%)
Prognostic Information Preferences	
Want to receive	64 (33%)
Not wanting to receive	132 (67%)
Patient Characteristics	
Age	55.29 (15.40)
Gender	
Female	118 (57%)
Marital Status	
Married	158 (76%)
Not married	49 (24%)
Years of education	8.50 (4.58)
Socioeconomic Status	
Low income	76 (37%)
Lower/upper middle or upper income	130 (63%)
Years knowing diagnosis	
1 year or less	42 (20%)
1 to 3 years	110 (53%)
More than 3 years	55 (27%)
Symptom burden	12.91 (7.08)
†Figures are in percentages unless indicated otherwise; Due to rounding, percentages may not add up to 100%.	

Table 2. Associations Between Prognostic Awareness and Patient Characteristics

	Coefficient	[95% Confidence Interval)
Patient Characteristics		
Age	-0.01	-0.03; 0.01
Years of education	-0.005	-0.08; 0.07
Lower-upper middle class (ref: low income)	-0.15	-0.53; 0.23
Symptom burden	0.01	-0.03; 0.06

p<0.05; **p<0.01; *p<0.001*

Table 3. Associations Between Patient Preferences for Prognostic Information and Patient Characteristics

	Coefficient	[95% Confidence Interval)
Patient Characteristics		
Age	0.04*	0.02; 0.06
Years of education	0.17*	0.07; 0.26
Lower-upper middle class (ref: low income)	-0.82***	-1.30; -0.35
Symptom burden	-0.06*	-0.11; -0.01

p<0.05; **p<0.01; *p<0.001*