

# Breaking Bad News in Cancer Care: Ethiopian Patients Want More Information Than What Family and the Public Want Them to Have

Aynalem Abraha Woldemariam, MD, PhD<sup>1†</sup>; Rune Andersson, MD, PhD<sup>2</sup>; Christian Munthe, PhD<sup>3</sup>; Barbro Linderholm, MD, PhD<sup>4</sup>; and Nataliya Berbyuk Lindström, PhD<sup>5</sup>

**PURPOSE** This study explores the preferences of patients with cancer, family caregivers, and the general public regarding breaking bad news in an Ethiopian oncology setting.

**METHODS** The study was conducted at Tikur Anbessa (Black Lion) Specialized Hospital. The sample consists of patients with a confirmed cancer diagnosis, their family caregivers, and representatives from the general public with 150 subjects per cohort. The study used a comparative cross-sectional design and multivariable data analysis.

**RESULTS** The patients would like to be informed, which contradicts the preferences of family caregivers. This creates an ethical dilemma for staff in terms of how much they involve their patients in clinical decision making. The patients also indicate that information should not be withheld from them. By contrast, the general public prefers information about poor life expectancy to be communicated to family only, which may reflect a widespread public perception of cancer as a deadly disease.

**CONCLUSION** The findings indicate the complexity of communication-related preferences concerning breaking bad news in oncology care in Ethiopia. It requires oncologists to probe patient attitudes before information disclosure to find a balance between involving patients in communication at the same time as keeping a constructive alliance with family caregivers.

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## INTRODUCTION

The aim of this study is to explore the preferences of Ethiopian patients with cancer, family caregivers, and the general public regarding breaking bad news and withholding such information in an Ethiopian cancer care setting.

Communication skills are essential to provide optimal patient care in general, and in the cancer context in particular. Addressing patients' needs and sharing complex information in an emotionally charged setting is a challenge, especially when bad news (ie, any information that adversely alters one's expectations for the future<sup>1</sup>) is broken.<sup>2-4</sup>

Cultural norms and social context influence patient and family preferences regarding the delivery of bad news in terms of whether a physician tells the truth, tells the whole truth, to whom, and how.<sup>5-7</sup> Previous research suggests that in non-Western societies, where 'filial culture' is widespread, patients are often accompanied by family members who prevent physicians from revealing bad news to patients.<sup>8-13</sup> By contrast, in the Western context, the recognized standard is that physicians inform

patients of facts relevant to care; patients can request that information is wholly or partly withheld from family caregivers, while the latter have no valid claim to restrict the patient's right to be fully informed.<sup>14,15</sup> Other studies show that preferences vary depending on what information is to be delivered. Although patients prefer getting information concerning cancer diagnosis, treatment, and a possible poor prognosis from oncologists, information about the transition from curative to palliative treatment and end-of-life outcomes is often told only to family, who favor withholding the truth from patients to avoid unnecessary distress.<sup>8,9,16</sup>

To better understand how clinical professionals and health care institutions should act, a good idea of actual attitudes in a specific regional setting is crucial as a baseline for guidelines and clinical policy. Although cancer is a growing concern in Ethiopia and sub-Saharan Africa,<sup>17-19</sup> oncology services are currently scarce.<sup>20,21</sup> Limited research is available relating to cancer care communication in Ethiopia in general, and in regards to patient and family preferences on breaking bad news in particular.<sup>21-25</sup> Earlier studies in different care settings in Ethiopia show the paramount role family

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## CONTEXT

### Key Objective

Little is known about communication in oncology care in Ethiopia, although cancer is a growing concern. What are the preferences of patients with cancer, family caregivers, and the general public regarding breaking bad news in an Ethiopian oncology setting?

### Knowledge Generated

The patients would like to be informed about diagnosis and poor prognosis, which contradicts the perceptions of family caregivers who prefer information is withheld from patients. The patients also want oncologists to not withhold information from them. The general public prefers information about poor life expectancy to be communicated to family only.

### Relevance

Communication skills are essential to providing optimal patient care. In oncology, breaking bad news is a challenge. Knowledge about preferences concerning breaking bad news can help oncologists in finding a balance between patient involvement in clinical decision making while keeping a constructive alliance with family members.

plays in patient care.<sup>24,26,27</sup> Reid et al<sup>27</sup> report that in the case of terminal illness, disclosure of bad news is discouraged, as family members believe that it may lead to unnecessary distress and loss of hope. Research at the Chemotherapy and Radiotherapy Center of Tikur Anbessa (Black Lion) Specialized Hospital in Addis Ababa (which is the only facility that provides radiotherapy services in Ethiopia) indicates that health-related information and, in particular, bad news are regularly withheld from patients, not seldom at the behest of family. Staff at this clinic also asked for more guidance regarding breaking bad news and how to handle family involvement.<sup>28</sup> This indicates a need to better understand the attitudes of patients, family care providers, and the general public in Ethiopia concerning the disclosure of bad news in cancer care. This improved understanding may guide oncologic care professionals in performing this task, and the development of improved management of related ethical dilemmas. To this end, this study focuses on:

1. Preferences concerning whom bad news is communicated to (directly to the patient, to the patient in the presence of family, or to family only).
2. Attitudes to communicating end-of-life decisions and withholding information from patients.

## METHODS

The study was conducted in 2019-2020 at the Chemotherapy and Radiotherapy Center of Tikur Anbessa (Black Lion) Specialized Hospital.<sup>29</sup> Currently, this clinic treats about 10,000 patients with cancer yearly, whereas the estimated annual incidence of cancer in Ethiopia is more than 60,000 cases.<sup>30-32</sup>

The study used a comparative cross-sectional design to analyze similarities and differences of attitudes to disclosure of clinical information among three groups: patients with a confirmed cancer diagnosis, family caregivers, and general public representatives with a self-reported lack of

cancer family history. These attitudes were assessed using a nine-item questionnaire, which included questions about demographics, respondents' perspectives on to whom the information should be delivered and withholding information from patients, and patient involvement in discussion of end-of-life decisions.

While the attitudes to physicians' disclosure of cancer status was considered the outcome variable, the following sociodemographic characteristics of the subjects were also recorded for possible correlation: age, sex, marital status, family size, educational level, occupation, and income. The questionnaire was prepared in English, translated to Amharic, and translated back to English from Amharic.

Sample size for the study was determined by using a formula for proportion in two populations. Considering respondents from each cohort have a varying attitude to disclosure by a physician, assuming about 50% of subjects in the caregiver group will hold that a physician should disclose directly to the patient, and assuming that this attitude will exceed by 25 percentage points in the patients' group, at 95% confidence level and 80% power, a total of 136 participants are needed. The sample size was increased by 10% to compensate for possible nonresponse and incompleteness. Therefore, a total of 150 participants per cohort (patients, family caregivers, and general public representatives) were included (450 participants in total).

The study used systematic random sampling to select participants for the patient and family caregivers cohort. Patients with a confirmed cancer diagnosis at the Chemotherapy and Radiotherapy Center of Tikur Anbessa Hospital and their family caregivers were invited to participate in the study. Participants were selected from newly diagnosed patients over a period of two months. Every second new patient was invited to participate in the study until the sample size was complete. Similarly, individual

participants from the general public at public places in Addis Ababa were selected conveniently, screened via the eligibility criteria, and invited to be involved.

The data were coded, cleaned, edited and entered into Epi-data version 3.1 to minimize logical errors, and then the data were exported to SPSS Windows version 25 for

analysis. The analysis was done by computing proportions and summary statistics for the three categories of subjects (patients, family caregivers, and general public representatives). The attitudes of each group to disclosure of cancer status and the involvement of family care providers were compared using the chi-square test. The association

**TABLE 1.** Sociodemographic Characteristics of Patients, Family Caregivers, and the General Public

Characteristics	Patients, No. (%)	Family Caregivers, No. (%)	General Public, No. (%)	$\chi^2$ (df, P)
Age grouped, years				69.544 (4, < .001)
18-29	17 (12.4)	75 (50.7)	50 (35.0)	
30-39	30 (21.9)	43 (29.1)	26 (18.2)	
> 40	90 (65.7)	30 (20.3)	67 (46.9)	
Mean $\pm$ SD	45.2 $\pm$ 13.5	31.5 $\pm$ 9.7	38.8 $\pm$ 12.9	
Sex				28.664 (2, < .001)
Male	47 (31.5)	93 (62.0)	64 (42.7)	
Female	102 (68.5)	57 (38.0)	86 (57.3)	
Marital status				47.313 (4, .0001)
Married	104 (70.7)	89 (59.3)	102 (66.0)	
Single	17 (11.6)	58 (38.7)	40 (26.7)	
Divorced or widowed	26 (17.7)	3 (2.0)	8 (5.3)	
Residence				19.602 (2, < .001)
Urban	124 (82.6)	132 (88.0)	147 (98.0)	
Rural	26 (17.4)	18 (12.0)	3 (2.0)	
Education				54.214 (4, .001)
Elementary or less	53 (35.8)	20 (13.3)	16 (19.9)	
Secondary school	49 (33.1)	65 (43.3)	37 (24.8)	
College or more	46 (31.1)	65 (43.3)	96 (64.4)	
Family size				5.990 (4, .200)
$\leq$ 3	55 (39.6)	47 (35.1)	53 (38.7)	
4-6	64 (46.0)	62 (46.3)	72 (52.6)	
$\geq$ 7	20 (14.4)	25 (18.7)	12 (8.8)	
Religion				7.910 (4, .095)
Christian	130 (87.8)	118 (78.7)	124 (83.8)	
Muslim	18 (12.2)	28 (18.7)	23 (15.5)	
Others	—	4 (2.7)	1 (0.7)	
Monthly income <sup>a</sup>				42.328 (6, < .001)
< 2,000	33 (22.3)	39 (26.2)	25 (16.7)	
2,001-6,000	58 (39.2)	30 (20.1)	18 (12.0)	
6,001-10,000	33 (22.3)	47 (31.5)	63 (42.0)	
$\geq$ 10,000	24 (16.2)	33 (22.1)	44 (29.3)	
Occupation				62.755 (6, .001)
Unemployed	46 (31.3)	29 (19.3)	24 (16.8)	
Self-employee	53 (36.1)	74 (49.3)	28 (19.6)	
Government employee	36 (24.5)	28 (18.7)	40 (28.0)	
Nongovernment employee	12 (8.2)	19 (12.7)	51 (35.7)	

Abbreviation: SD, standard deviation.

<sup>a</sup>Ethiopian Birr (ETB).

between sociodemographics, types of subject, and attitudes was generated by binary logistic regression. For the multivariable analysis, variables that were associated with the outcome variable or in borderline with a *P* value below .25 in the univariable analysis were included. A multicollinearity test was conducted to see the correlation between independent variables by using variance inflation factor and standard error. The direction and strength of statistical associations were measured by odds ratios (ORs) with 95% CI. *P* values below .05 were considered to be statistically significant.

The study has been approved by the Department of Oncology, School of Medicine, College of Health Sciences, Addis Ababa University (protocol Number ONC IRB 27). Informed consent was obtained from each participant after informing them about the objectives, risks, and benefits of the study. Participants were informed that participating in the study was voluntary, and of their right to withdraw at any time. We ensured participant privacy and confidentiality throughout the study.

## RESULTS

The sociodemographic characteristics of the three populations are presented in [Table 1](#).

The patients were slightly older than the participants from the other groups, and more were women.

The majority of respondents in all cohorts preferred that oncologists communicate information such as the inability to source drugs for cancer (locally and globally), treatment failure, and poor life expectancy to patients in the presence of family, or to family only ([Table 2](#)). Approximately 73% of respondents from the general public cohort considered that information about life expectancy should be delivered to family only, who can then decide whether to pass this information on to the patient or not, compared with 15% of patients and 23% of family caregivers. The majority of respondents preferred that oncologists communicate information concerning a poor prognosis to family only, but this is the only type of bad news where a majority of patients expressed such a preference. Only 3% of family caregivers

**TABLE 2.** Preferences Concerning Communicating Bad News

Questionnaire Items	Communicate Directly to the Patient, No. (%)	Communicate to the Patient in Presence of Family, No. (%)	Communicate to Family Only, No. (%)	$\chi^2$ (df, <i>P</i> )
Information about cancer diagnosis				79.9 (4, .00001)
Patients	52 (35)	81 (55)	15 (10)	
Family caregivers	7 (5)	49 (38)	74 (57)	
The general public	29 (20)	61 (42)	55 (38)	
Information about poor prognosis				24.6 (4, .000062)
Patients	22 (15)	32 (22)	94 (63)	
Family caregivers	3 (3)	12 (12)	88 (85)	
The general public	15 (11)	40 (30)	77 (58)	
Information about life expectancy				110.9 (4, < .00001)
Patients	38 (26)	88(60)	22 (15)	
Family caregivers	24 (17)	83 (60)	31 (23)	
The general public	12 (11)	19 (17)	82 (73)	
Information about failure of treatment				10.4 (4, .03)
Patients	28 (19)	52 (35)	68 (46)	
Family caregivers	19 (16)	30 (26)	68 (64)	
The general public	13 (10)	34 (26)	82 (64)	
Inability to source drugs locally				18.5 (4, .001)
Patients	13 (9)	96 (65)	39 (26)	
Family caregivers	10 (8)	57 (44)	62 (26)	
The general public	13 (10)	58 (45)	59 (45)	
Inability to source drugs globally				14.9 (4, .005)
Patients	10 (7)	80 (54)	58 (39)	
Family caregivers	12 (10)	37 (40)	59 (50)	
The general public	8 (7)	51 (43)	60 (50)	

**TABLE 3.** Attitudes to Withholding Information and Communicating End-of-Life Decisions

Questionnaire Items	Patients, No. (%)	Family Caregivers, No. (%)	The General Public, No. (%)	$\chi^2$ (df, P)
Oncologists should not withhold information from patients				47.958 (8, .0001)
Strongly agree	52 (35)	38 (25)	31 (21)	
Agree	51 (34)	18 (12)	40 (27)	
Neutral	19 (13)	24 (16)	27 (18)	
Disagree	25 (17)	48 (32)	42 (28)	
Strongly disagree	2 (1)	22 (15)	10 (7)	
Oncologists should involve patients in end-of-life decisions				12.620 (8, .126)
Strongly agree	33 (22)	34 (23)	26 (17)	
Agree	31 (21)	31 (21)	43 (29)	
Neutral	21 (14)	14 (9)	13 (9)	
Disagree	33 (22)	46 (31)	49 (33)	
Strongly disagree	31 (21)	25 (17)	19 (13)	

preferred that an oncologist communicated news about a poor prognosis to the patient directly.

The results also indicate that patients have contrasting preferences to family caregivers and the general public regarding how news about cancer diagnosis and poor prognosis should be delivered. Although the majority of patients would like to be informed directly or in the presence of family, the dominant preference of family caregivers and the general public is that this information is communicated to the family only. Regarding information about a cancer diagnosis, 10% of patients considered that this should be delivered to the family only compared with 57% of the family caregivers and 38% of the general public representatives. Only 5% of the family caregivers and 20% of the general public preferred the information about diagnosis to be delivered directly to the patients.

The results concerning attitudes to involving patients in end-of-life decisions and withholding information from patients are presented in Table 3.

On the question concerning withholding information, most patients (69%) compared with 37% of family caregivers and 48% of general public agree that the information should not be withheld from the patients. The difference was significant ( $P = .0001$ ). On the multiple-choice question concerning attitudes about involving patients in discussions about end-of-life decisions, no significant differences were observed between cohorts, but a stark divide in opinions across cohorts was evident. About half of the respondents in all cohorts strongly agreed that the patients should be involved, whereas the other half strongly disagreed. The family caregivers cohort were the most critical concerning revealing information (47% compared with 18% of patients).

In the multivariable analysis, family caregivers and the general public were less likely to hold that physicians

should disclose cancer status directly to patients than the patients were (adjusted OR = 0.21; 95% CI, 0.11 to 0.41 and adjusted OR = 0.32; 95% CI, 0.17 to 0.60, see Table 4). The ORs were adjusted for cohort type, age group, sex, residence, and monthly income. Women were more likely to prefer physician disclosure of cancer status to patients than men in univariate analysis, but the association was not significant after adjusting for confounding of other background variables.

## DISCUSSION

Although the respondents in all cohorts generally prefer the disclosure of bad news is given to either patients in the presence of family or to family only, attitudes to the disclosure of *different types of* bad news vary widely between the cohorts, in particular regarding the withholding of information from patients. This adds to the clinical ethical complexity noted at the outset, as it may very well be the case that patients prefer to receive certain types of bad news, but not others, while family caregivers may have different preferences.

The similarities and differences between attitudes of the patients, the family caregivers, and the general public in Ethiopia add a further layer to this complexity. While a majority of patients preferred to be involved in interactions, opposing that physicians withhold information from them, the opposite was true for the majority of the family caregivers and the general public. This is in accordance with previous studies claiming that family members may attempt to protect patients from accessing information they fear might upset or distress them, or otherwise affect their mental health negatively.<sup>12,33</sup> This possibly protective stance was also observed in the responses concerning preferences about disclosure of diagnosis. Although the majority of patients preferred to be told the diagnosis either directly or in the presence of family, the majority of family

**TABLE 4.** Univariable and Multivariable Adjusted ORs for Preferred Disclosure of Cancer Status by Physicians to the Patients

Characteristics	Crude OR (95% CI)	Adjusted <sup>a</sup> OR (95% CI)
Cohort		
Patients	1.00	1.00
Care provider	0.19 (0.12 to 0.32)	0.21 (0.11 to 0.41)
General public	0.29 (0.18 to 0.48)	0.32 (0.17 to 0.60)
Age grouped, years		
18-29	1.00	1.00
30-39	1.02 (0.61 to 1.70)	0.86 (0.46 to 1.59)
> 40+	1.20 (0.78 to 1.86)	0.72 (0.41 to 1.28)
Sex		
Men	1.00	1.00
Women	1.54 (1.06 to 2.24)	1.23 (0.75 to 1.99)
Marital status		
Married	1.00	Not tested
Single	0.78 (0.51 to 1.20)	
Divorced or widowed	1.20 (0.60 to 2.41)	
Residence		
Urban	0.63 (0.34 to 1.18)	0.68 (0.32 to 1.46)
Rural	1.00	1.00
Education		
Elementary or less	1.00	Not tested
Secondary school	0.85 (0.50 to 1.44)	
College or more	1.00 (0.61 to 1.65)	
Monthly income <sup>b</sup>		
< 2,000	1.00	1.00
2,001-6,000	1.74 (0.99 to 3.08)	1.39 (0.71 to 2.74)
6,001-10,000	0.98 (0.59 to 1.64)	1.08 (0.58 to 2.04)
≥ 10,000	0.85 (0.49 to 1.49)	1.09 (0.53 to 2.340)

Abbreviation: OR, odds ratio.

<sup>a</sup>Adjusted for cohort type, age group, sex, residence, and monthly income.

<sup>b</sup>Ethiopian Birr (ETB).

caregivers and a large proportion of the general public considered that only family should be told.

## AFFILIATIONS

<sup>1</sup>Department of Surgery, School of Medicine, Health Science College, Addis Ababa University, Addis Ababa, Ethiopia

<sup>2</sup>Department of Infectious Diseases, Institute of Biomedicine, The Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

<sup>3</sup>Department of Philosophy, Linguistics and Theory of Science, University of Gothenburg, Gothenburg, Sweden

<sup>4</sup>Institute of Clinical Sciences, Department of Oncology, The Sahlgrenska Academy, University of Gothenburg and the Sahlgrenska University Hospital, Gothenburg, Sweden

Together, these aspects complicate the ethical challenge reported by the oncologic care professionals at Tikur Anbessa, reported in earlier studies.<sup>28</sup> In the background are possible cultural factors, for instance, that in Ethiopia, as in many countries, a cancer diagnosis comes with social stigma and misperceptions,<sup>27</sup> or that family attitudes allow concealing information from family members, eg, for alleged caring purposes.<sup>34</sup> Thus, cultural constraints may impede health professionals from meeting patients' preferences concerning cancer information disclosure.<sup>35</sup> This might explain why, in Ethiopia, oncologists typically adhere to family preferences, rather than making sure that the individual patient's preference is made clear and satisfied.<sup>35,36</sup> When the issue of nondisclosure in family-oriented cultures is debated in the medical ethical literature, the question is typically whether the patient should be told, in addition to the family, assuming a cultural hegemony.<sup>37</sup> Our results indicate reasons to doubt this assumption. In the family-oriented culture of Ethiopia, we have found a significant gap between preferences for prognostic disclosure among cancer patients, family caregivers, and the general public, on the one hand, and the actual reporting of prognosis to patients by care professionals, on the other.<sup>25,38,39</sup> Patients with cancer who are not told their prognosis may have several negative consequences, including inappropriate prognostic awareness, receiving futile treatment at the end of life, being unprepared for death, increased psychologic and mental distress as well as social and spiritual suffering, and decreased quality of life.<sup>40</sup> In addition, as patients may not share the preferences of their family caregivers, or of the general public, in relation to breaking bad news, an Ethiopian oncologic health professional, who proceeds on the assumption that they do, runs a serious risk of unwittingly disrespecting their medical ethical duty to their patients.

In conclusion, the findings of this study indicate the complexity of communication concerning breaking bad news in oncology care in Ethiopia. It requires oncologists and hospital staff to establish clinical routines that allow them to probe patient attitudes about information disclosure to find a balance between involving patients in communication at the same time as keeping a constructive alliance with family caregivers.

<sup>5</sup>Department of Applied Information Technology, University of Gothenburg, Gothenburg, Sweden

†Deceased.

## CORRESPONDING AUTHOR

Nataliya Berbyuk Lindström, PhD, University of Gothenburg, Forskningsgången 6, SE-412 96 Gothenburg, Sweden; e-mail: nataliya.berbyuk.lindstrom@ait.gu.se.

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**AUTHOR CONTRIBUTIONS**

**Conception and design:** All authors

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**Collection and assembly of data:** Aynalem Abraha Woldemariam, Christian Munthe, Nataliya Berbyuk Lindström

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**AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST**

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**Barbro Linderholm**

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