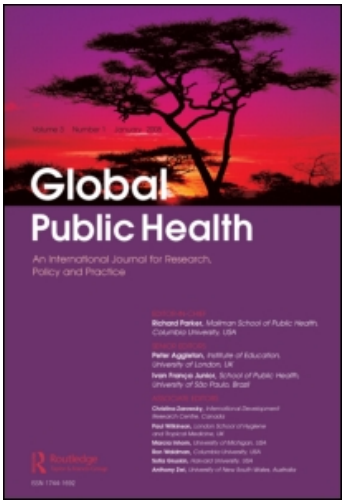

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A mixed-method assessment of beliefs and practice around breast cancer in Ethiopia: Implications for public health programming and cancer control

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A mixed-method assessment of beliefs and practice around breast cancer in Ethiopia: Implications for public health programming and cancer control

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A large proportion of breast cancer patients in Ethiopia present for biomedical care too late, or not at all, resulting in high mortality. This study was conducted to better learn of beliefs and practices among patients accessing breast cancer services in a large referral centre in Ethiopia. Using a mixed-method design, we interviewed 69 breast cancer patients presenting for care at Tikur Anbessa Hospital in Addis Ababa, Ethiopia, about their beliefs, experiences and perspectives on breast cancer. Awareness of breast cancer is low in Ethiopia and even among those who are aware of the disease, a sense of hopelessness and fatalism is common. Early signs/symptoms are frequently ignored and patients often first present to traditional healers. Breast cancer is perceived as being caused typically from humoral anomalies or difficulties resulting from breast feeding, and study participants indicate that stigmatisation and social isolation complicate discussion and action around breast cancer. Consistent with other studies, this study shows that traditional beliefs and practices are common around breast cancer and that numerous barriers exist to identification and treatment in Ethiopia. Integrating health beliefs and practice into public health action in innovative ways may reduce stigma, increase awareness and promote survivability among breast cancer patients.

Keywords: Ethiopia; breast cancer; qualitative; ethnomedicine; beliefs

Introduction

Breast cancer is a leading cause of death among women worldwide (World Health Organization [WHO] 2008), including in low- and middle-income countries, and its incidence is growing (Garcia *et al.* 2007). In many parts of the world experiencing rapid epidemiologic transition, breast cancer is increasingly more visible (Robles and Galanis 2002) as the burden of infectious disease declines (Economic and Social Commission for Asia and the Pacific [ESCAP] 2007). The effective treatment of

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breast cancer depends upon a complex chain of encounters with the medical system, from prevention, screening and detection, to an intricate set of treatments including radiology, surgery and chemotherapy (Anderson *et al*. 2006a). Mortality from breast cancer is significant if left untreated or with treatment significantly delayed (Carlson *et al*. 2003). These delays lead, understandably, to the firm establishment of cultural notions surrounding breast cancer that emphasise its resistance to treatment (Dein 2004) at late stages and a limited sense of personal locus of control (Joy *et al*. 2005) surrounding outcomes. In many developing countries, particularly within Africa, most women with breast cancer die of the disease (Ferlay *et al*. 2004) complicated by late diagnosis and insufficient access to adequate treatment (Gakwaya *et al*. 2008).

The full spectrum of developing and adapting optimal programmatic and treatment recommendations for breast cancer control in developing countries, while emerging, is complex and challenging (Love 2008). Understanding beliefs, cultural constructs and decision-points around breast cancer is crucial for structuring effective cancer control plans and public health programming in developing countries (WHO 2006). Simply adopting strategies and technologies from high-income or high-resource countries will not prove effective in lower income countries that differ significantly in social, health care and human resource conditions and capacities (Anderson *et al*. 2006b). Knowing how breast cancer is perceived and viewed by affected populations is key in developing programmes that encourage early detection and treatment (Ahmad *et al*. 2005), which considerably improves survival (Smith *et al*. 2006). The objective of this paper is to elucidate beliefs and attitudes towards breast cancer in Ethiopia to help inform development of public health programmes that address cancer prevention and reduction.

Methods

This project adopted a systematic qualitative participatory approach, nested within a larger overall effort to better understand the impact of the Ethiopia Breast Cancer Project (EBCP). EBCP aims to strengthen human resource capacity, technical competency and advocacy, and improve access to treatment for breast cancer in Ethiopia, working closely with all related Departments and services of Tikur Anbessa Hospital (TAH), the Ministry of Health and the Ethiopian Cancer Association (Reeler *et al*. 2008). Patients, their families, and health practitioners were interviewed as part of the larger impact assessment using semi-structured interview protocols which were developed following open-ended ethnographic interviews and observations.

The data teams consisted of four senior medical students, fluent in written and spoken Amharic and English, who located and interviewed respondents. The data teams participated in a one-day training session that included: study overview, ethical conduct of research, role play and pilot test interviews and review. The teams were debriefed each day with investigators for major points and discussion items for the group. Qualitative data were analysed through theme analysis predominantly using ATLAS.ti (Version 5.5) and quantitative data were analysed using JMP (Version 8). Where necessary, translated English grammar in direct quotes is corrected from transcriptions to ease readability and placed in the first person context, though content remains unchanged.

Sample characteristics

Patients presenting at TAH for breast cancer care were randomly selected over the span of 1 month to provide consent to participate in this study. Participant characteristics are presented in Table 1. In total, 55 patients directly participated in the study, in addition to 14 proxies (children, spouses and others) representing other patients, for a total of 69 patients represented. Most participants were married and female, and more than half were age 50 years or younger. About two-thirds of participants lived in Addis Ababa, and almost three-quarters of the population were Ethiopian Orthodox. Two-thirds of the participants were diagnosed with breast cancer in the immediate 2 years prior to the assessment. The average interview lasted 41 minutes. When compared to the clinic treatment population for the first half of

Table 1. Characteristics among breast cancer programme assessment participants, Ethiopia.

Variable	*n*	%
Gender		
Female	67	97.1
Male	2	2.9
Proxy respondent		
Yes, other family	14	20.3
No, self	55	79.7
Respondent age (years)		
< 40	26	37.7
41–50	18	26.1
51–60	10	14.5
61–70	4	5.7
Unknown	11	15.9
Residence		
Addis	45	65.2
Outside Addis	22	31.9
Unknown	2	2.9
Religion		
Ethiopian Orthodox	50	72.5
Muslim	10	14.5
Christian	9	13.0
Marital status		
Married	45	65.2
Not married	16	23.2
Unknown	8	11.6
When diagnosed with breast cancer		
Before 2003	1	1.4
2003–2005	12	17.4
2006	23	33.3
2007	30	43.5
Unknown	3	4.3

2008 from EBCP programmatic data (unpublished), the study sample did not differ significantly from the clinic treatment population on any of the following parameters: age, gender or residence of patient.

Ethical review

This project was reviewed and approved by the Addis Ababa University Faculty of Medicine IRB. Additionally, project team members were trained in research ethics using materials from the CitiProgram (http://www.citiprogram.org). Participant names were not collected as part of this project, and indirect identifying information was grouped and presented in general categories or in aggregate.

Results

Attitudes

Close to half of the study participants ($n = 33$; 47.8%) indicate that women in Ethiopia typically know nothing about breast cancer and, in fact, have often never heard of the disease at all. Many respondents ($n = 24$; 35%) mentioned that lack of knowledge was a major problem facing breast cancer patients in Ethiopia:

> I did not react when told the bad news as I had never heard of it [breast cancer] before... (Participant 62)

> I hadn't heard of the disease before and didn't come across with anyone talking about it. (Participant 69)

The first clear theme that emerges when speaking with patients and families about cancer is a general sense of fatalism, and that the disease is not treatable. In fact, approximately 40% of the respondents indicated this attitude of fatalism when describing their own beliefs and stories, many of whom ignored early signs of their breast cancer and/or delayed getting care:

> The only man I talk with about it [breast cancer] is my husband, and his feeling is like me: he thinks that I will die soon ... (Participant 27)

> All believe it [breast cancer] is a killer with no cure ... When I told my family I had a cancer, they were all shocked and hopeless about me. I am not that much shocked because I believe in God, and he is the only one who decides when to die. (Participant 45)

This general sense of fatalism often persists, even in the context of treatments being available for breast cancer, noted below:

> The society thinks that people who have cancer are hopeless, even if they are treated. (Participant 53)

> It [breast cancer] is a killer and doesn't get cured by medicine. (Participant 41)

> I think that I cannot be cured and that I am taking the drugs to sustain my remaining life ... (Participant 47)

Related, this sense of fatalism and the perceived futility of treatments can impact patients' decisions to (or not to) seek care. In particular, patients and their families avoid health facilities at times because they don't perceive that the disease itself is treatable:

> There is a great lack of awareness that every one believes that breast cancer is not curable so they didn't come to the health center. (Participant 15)

> People don't know that a person can be treated for cancer and survive, so they tend to go to traditional healers than medical facilities, which makes it worse. (Participant 64)

Conversely, some participants and their families feel optimism given that treatments are available for breast cancer, especially as they begin to feel better after surgical and chemotherapy treatments:

> At first it was hard because I just thought that it cannot be cured. But after the treatment and seeing the change that it has had, at least now I am feeling better and starting to believe that I can be cured. (Participant 47)

> Earlier when I heard of the word 'cancer' it was associated with immediate death. Now I believe that it is just a disease like the others that can be cured. (Participant 67)

Patients and families mention several dimensions of stigma, including isolation and taboos on discussing cancer. Approximately 10% of participants indicated that stigmatisation and isolation were major problems faced by breast cancer patients in Ethiopia:

> No one wants to talk about it, it seems as if it's forbidden to talk about and raise. (Participant 29)

> Some try to hide it. (Participant 34)

> Due to a lack of knowledge, when they hear the word 'cancer' they get scared, some hide it and some use traditional medicine until it becomes too late for treatment. (Participant 4)

> Sometimes they [breast cancer patients] have a bad odor and they get isolated from the society. (Participant 54)

Causation

As shown in Table 2, overall when asked what they feel causes breast cancer, most participants ($n = 38$; 55.1%) gave an 'ethnomedical'[1] cause. The most common singular cause of breast cancer noted by participants was *mich* (an Ethiopian ethnomedical category roughly equivalent to 'bad air'), followed by breast feeding problems (either lack of breast feeding, retained breast milk or uneven breast feeding) and other humoral causes (exposure to heat, exposure to sunlight and exposure to cold). Following ethnomedical causes, the next most common response participants indicated when asked what caused breast cancer was 'don't know', again reflecting general lack of awareness of breast cancer, as previously discussed. A group of 'biomedical'[1] causes including heredity, diet and environment accounted for responses given by 27.5% of participants. Six participants indicated both ethnomedical and biomedical causes when responding to this question. Participant likelihood

Table 2. Stated causes of breast cancer among Ethiopian breast cancer patients and their proxies.[a]

Cause	*n*	%
Mich	15	21.70
Breast feeding problem	12	17.40
Genetic/hereditary	10	14.50
Sunlight	8	11.60
Poor diet	8	11.60
Cold exposure	4	5.80
Curse	4	5.80
Heat exposure	3	4.30
Don't know	21	30.40
Biomedical cause	19	27.50
Ethnomedical cause	38	55.10

[a]Multiple responses allowed; overall sample $n = 69$.

of indicating an ethnomedical cause for breast cancer was not associated with religion (Christian/ Orthodox/Muslim), residence (Addis Ababa/ Other) or woman's age.

Participants who indicated an ethnomedical cause, however, were significantly more likely to ignore the early signs of their disease. Overall, 64% of participants who indicated an ethnomedical cause ignored early signs of their disease, while 36% of participants who did not indicate an ethnomedical cause ignored early signs of their disease ($p < 0.05$). Further, although most sought care first from the health system, participants indicating an ethnomedical cause for breast cancer were more than 2.5 times more likely to initially see a traditional healer for their symptoms.

Ethnomedical causes of breast cancer

Two ethnomedical causes of breast cancer that are mentioned commonly among the patient population involve issues around breast feeding and also around the humoral Ethiopian construct of *mich*,[2] which respondents indicate may work with several other factors to produce breast cancer. The most commonly cited of all causes named by respondents involves humoral categories, including exposure to cold, sunlight, heat and *mich*, often described as follows:

> I believe the cause is mich, which is due to sudden exposure to sunlight. (Participant 25)

> The temperature is hot in my village and I usually expose my breast to the sun. I think this is the cause... (Participant 27)

> Mich, followed by sunlight exposure. (Participant 66)

> Most believe it's caused from mich and is a killer and it isn't cured by medicine. (Participant 41)

An important additional common perception is that breast cancer is caused by aberrations in breast feeding mechanisms, either with premature termination of breast feeding, the incomplete expression of breast milk or the lack of breast feeding generally. For instance:

> Retention of milk in my breast after I stopped breast feeding my last child. (Participant 45)

> After stopping lactating, the milk is not fully evacuated and it results in breast cancer. (Participant 15)

> I didn't lactate after I birthed my first child so milk accumulated. I think this accumulated milk caused breast cancer. (Participant 40)

> Mich, not lactating, and not giving birth can all cause breast cancer. (Participant 22)

Several other generally ethnomedical causes are put forth from respondents; in several instances, participants related to symptoms acquired through work, in the workplace:

> I carry big things so the blocking of blood vessels must be the cause. (Participant 41)

> I sometimes serve as a maid, and I wash clothes and cook for difficult families. I think this can cause the disease. (Participant 44)

As shown previously in Table 2, a variety of biomedical concepts of causation are also mentioned, albeit less frequently, by breast cancer patients and their families, often in connection with ethnomedical causes. These biomedical concepts usually surround notions of heredity and the passing of risk for the disease, or the disease itself, across generations, or less commonly around smoking and diet:

> It is passed from generation to generation. (Participant 13)

> Addiction of cigarettes... (Participant 28)

> I ate a lot of fatty food – it might predispose me. (Participant 15)

Such biomedical causes are sometimes combined with ethnomedical (usually, humoral) notions of causation, such as:

> I don't know anything. I don't know. But my mom told me it is cold. I heard smoking causes breast cancer... (Participant 51)

> Unbalanced diet, stress could be a cause. Sweating followed by sun rays and an allergic reaction. (Participant 29)

Finally, the concept of contagion or transmissibility of breast cancer from one to another is also occasionally mentioned as a mechanism for acquiring the disease:

> People believe it is transmittable like HIV. Some may also perceive it as HIV, because it is a debilitating disease. (Participant 54)

> I slept with a relative who transmitted the disease to me. (Participant 5)

Traditional medicine and healers

Table 3 presents use of traditional medicine before, during and after biomedical treatment, and also by religion. Overall, more than half of the participants in this study used traditional medicines at some point during their experience with breast cancer, with the largest proportion (24.6%) using traditional medicines before they

Table 3. Use of traditional healers/medicine before, during and after.

Timing of traditional medicine use	Total ($n=69$)	Religion		
		Orthodox ($n=50$)	Muslim ($n=10$)	Other Christian ($n=9$)
Before biomedical care	17 (24.6%)	15 (30.0%)	2 (20.0%)	0 (0.0%)
During biomedical care	13 (18.8)	13 (26.0)	0 (0.0%)	0 (0.0%)
After biomedical care	8 (11.6)	8 (16.0)	0 (0.0%)	0 (0.0%)
At any time before, during or after care	40 (58.0)	27 (54.0)	2 (20.0)	0 (0.0%)

accessed medical care at a clinic or hospital. A strong relationship exists between religion and use of traditional medicine in Ethiopia, with participants who were Orthodox Christians statistically significantly more likely to use traditional medicines than either Muslim or Other Christian participants. Use of traditional medicine declined as the biomedical care process began, with more than half of participants indicating they stopped using traditional therapies by the time their biomedical care had finished or reached maintenance phase. About one in five participants used traditional therapies concomitantly with biomedical treatment.

The decision to see a traditional healer is complex, related to notions of causation and beliefs. People often stressed the changing nature of Ethiopian society, with more pressure to go into the biomedical system for treatment of a disease like cancer rather than seeing a traditional healer first. For others who chose to see a traditional healer, often their experience complicates their medical condition, causing more urgent situations:

> Most [women] don't know about it [breast cancer]. Those who know about it believe that traditional healers are the solutions, but recently some changes are starting to be seen regarding people's beliefs. (Participant 17)

> Around three years ago, I started to experience an itching sensation over my right breast which later on worsened and became a lump around the nipple and with pricking type of pain. Then I went to a local healer where I took some medications for 30 days. After the herbal medications my breast burst massively and prompted me to go to the hospital... (Participant 44)

The most commonly indicated traditional therapy taken is holy water, and to a lesser extent, holy mud or holy soil. Use of holy water is common in Ethiopia and is often the first step once symptoms are noticed and sometimes continues throughout and after biomedical treatment. Participants who indicated they used holy water or holy mud commonly report they ignored early signs and symptoms of breast cancer:

> ... I didn't go to local healers but I drink holy water all the time. (Participant 52)

> I usually took holy water even before the medication and I am still taking it. Otherwise, I don't take other medications. (Participant 14)

> I didn't visit the local healer but always drink holy water and also apply emnet (holy mud) on my breast. (Participant 69)

Discussion

In Ethiopia, as in much of the world, cancer is not only increasingly burdensome from a public health perspective (Mathers and Loncar 2006), but also is increasingly treatable as new technologies and medications become accessible to its population (Reeler *et al*. 2008). Best estimates show that mortality from breast cancer in Ethiopia is likely very high when compared with other countries, even neighbouring countries with similar economic profiles (Ferlay *et al*. 2004). The economic context of Ethiopia presents serious challenges to health systems in a country where health indicators are very poor, and where women's health issues, in particular, are significant (Central Statistical Agency 2006). Towards improving the health system response to breast cancer, this analysis aims to better understand the culture, beliefs and practices surrounding breast cancer among patients who are currently accessing treatment in the only comprehensive breast cancer treatment facility in Ethiopia, indeed only one of a small few in the entire region of Africa.

Not unlike many other countries of the world, awareness of breast cancer's signs and symptoms, treatment options, prognosis and prevention in Ethiopia is low. This study finds that awareness of breast cancer is low and unclear, which has been similarly documented in other studies of breast cancer in the region (Alemayehu 2008). Most participants in this project mentioned that while they noticed their initial symptoms, whether a lump, rash or pain, they were unaware that these were early signs of breast cancer. Frequently, participants indicated that they waited until the symptoms became bothersome or problematic (with or without having seen a traditional healer) before seeking medical care. Clearly, the fact that many of the participants in this present study in Ethiopia ignored early signs and symptoms of breast cancer indicates that awareness of breast cancer generally, and awareness of the impact of early detection and treatment on a better prognosis and course of the disease specifically, is very limited. In fact, other research in Ethiopia shows consistently that vast majority of patients presenting for breast cancer treatment are in advanced stages of the disease (Gebremedhin and Shemebo 1998, Ersumo 2006).

One of the predominant perspectives that commonly exists around breast cancer in Ethiopia is a sense of fatalism and hopelessness. In fact, this sense of fatalism is often the most significant barrier to awareness of breast cancer, discussions around it and programmes supporting early detection and treatment (Austin *et al.* 2002). In Ethiopia, as in many other low-income countries, breast cancer is perceived to be fatal, and as such, there is little incentive to seek biomedical or aggressive treatment (Ekotarl *et al.* 2007, Alemayehu 2008). As in the rest of Africa, in Ethiopia by the time a woman is diagnosed at a late stage with breast cancer she is, in fact, likely not to survive the disease. Thus, the perception that breast cancer in Ethiopia is fatal and (at least until recently) not readily treatable, is understood in this context. A recent global survey conducted by the International Union Against Cancer (UICC 2008) found that people in low- and middle-income countries commonly express pessimism and disbelief about the curability of cancer: indeed, 48% of respondents in low-income countries either said that not much can be done, or that they didn't know if anything could be done in the case of cancer (UICC 2008).

Concomitant with low awareness and a sense of fatalism, this study found that ethnomedical notions of causation were common, as has been found in other areas of Africa (Moore 2006). A significant component of notions and practice surrounding

breast cancer involve ethnomedical ideas and seeking traditional therapy. As found in this current study, others have noted that in Ethiopia cancer is often assumed to have spiritual or other non-medical causes, commonly leading breast cancer patients to seek advice from traditional healers or priests (Ekotarl *et al*. 2007). As this present study found, concurrent practice of traditional thoughts and treatments with biomedical notions of cancer and treatment is common in Ethiopia (Beyene 1992). Ethiopians commonly ascribe local causes of breast cancer, especially *mich* and problems with accumulated milk from breast feeding, and frequently seek traditional therapies prior to biomedical treatment. Especially in the Ethiopian context, humoral notions around the cause of breast cancer are particularly strong, embodied in the concept of *mich*. *Mich* has been scantly described in the literature (Giday *et al*. 2007, Teklehaymanot and Giday 2007, Wondimu *et al*. 2007) and its exact involvement as related to cancer is unclear. In the context of Ethiopia, where one of the oldest forms of Christianity (the Orthodox Ethiopian Church) is practiced, traditional healing practices are particularly strong and interwoven with religious belief and practice (Kassaye *et al*. 2006).

Traditional medical practice is common in Ethiopia (see Kassaye *et al*. 2006), across the spectrum of religions found there. In particular, consumption of holy water is a common first step when one is faced with a problem, and reflects the close integration of religious and medical belief. While urbanisation and the proliferation of modern medicine has caused some decline in traditional healer's generally high status in society (Teshome-Bahiru 2005), healers are still a visible and common component of Ethiopian society and are regularly accessed for a wide variety of conditions. [While some components of traditional Ethiopian healing, for instance invasive surgical practice, have come under greater scrutiny (Jeppsson *et al*. 2003), and it is now widely perceived that the integration of traditional healers would help promote preventive practices among the population, rather than engaging in direct treatment and intervention.]

Again, likely because of the poor prognosis and course of disease when diagnosed too late, participants in this study often explain that they feel a sense of isolation and stigma, and avoid getting diagnosed, hide their diagnosis once made, or become embarrassed by their symptoms. This same experience of stigma is documented elsewhere in Ethiopia (Beyene 2002), in that women are reluctant to disclose their status due to isolation and the potential for social exclusion. The strong propensity reflected in this current project for participants to ignore early symptoms perhaps reflects this stigmatisation and isolation. As such, a culture of avoidance and stigma perpetuates, though as more and more patients with breast cancer are detected early, are successfully treated and survive, the stigma affiliated with breast cancer may in fact decline. Organisations like the Ethiopian Cancer Association that create opportunities for patients to interact socially and speak publicly, are key in promoting these concepts of early diagnosis, treatment and the potential for survival.

Clearly, indigenous ideas around the cause and treatment of disease are complex and embedded thoroughly within a culture (Dein 2004). It may be useful to learn more about traditional practices surrounding breast cancer treatment, and quite possibly to engage traditional practitioners in a manner that promotes early referral to biomedical practitioners, perhaps concomitantly with non-invasive practices like consumption of holy water. Over half of the participants in this study engaged in

traditional practices before, during, or after their treatment; clearly, these practices are deeply held in the population and introducing biomedical ideas will be challenged in that breast cancer is not commonly seen to be biomedically caused, and sites of biomedical practice (i.e., clinics and hospitals) may be associated with end-stage disease. Exploring overlaps and opportunities to encourage early diagnosis and biomedical treatment by integrating useful ideas from both traditional and modern beliefs and practice could potentially significantly improve survival through earlier more effective treatment. Many examples exist of traditional healers and ideas successfully being integrated into referral systems and awareness-raising efforts for biomedical conditions such as cancer (Brown 1998, Hahn 1999). Traditional medicine and healers in Ethiopia often function, from the population's perspective, most effectively with certain diseases (Berhane *et al*. 2001). Perhaps as breast cancer patients in Ethiopia are identified earlier and can access effective treatment, populations will more readily access biomedical care.

This assessment provides new information on the experience, beliefs and attitudes towards breast cancer in an African population. There are, however, limitations to this study. First, the participants from the study are drawn from people who have successfully accessed cancer care; we cannot assume that these participants are the same as those who do not access care, nor may ever have their cancer diagnosed. Second, since breast cancer is often a stigmatising condition, it may be that participants did not disclose fully their beliefs or attitudes to interviewers, for fear of embarrassment or further stigmatisation. This type of assessment of existing cancer patients, however, is useful in providing baseline information to help inform public health programming, and should be viewed as a first step in learning more about beliefs and attitudes around cancer in a population.

In conclusion, awareness and education campaigns are crucial in communicating with populations about the importance of cancer, screening and the promise of early detection and treatment (Institute of Medicine 2007). With knowledge of target population beliefs and attitudes, such as the type this project identified, more specific messaging can be developed to improve the probability of reaching people with appropriate messages about cancer. The experience of un- or under-treated cancer patients in many countries has understandably created fear, stigma and feelings of desperation in many families and communities; concomitantly implementing public health education campaigns while improving basic diagnostic, treatment and palliation capacity and systems, would dramatically assist countries in reducing morbidity and mortality attributable to cancer.

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Notes

1. This analysis adopts a basic distinction between 'ethnomedical' and 'biomedical', reflecting Fabrega (1975) that roughly equates 'ethnomedical' with folk categories and indigenous (emic) perspectives and the latter with more western (etic) perspectives on modern medicine.

2. *Mich* is an Ethiopian construct that roughly corresponds to conditions created by the clash of cold and hot air, or the sudden exposure to air, or 'bad' air (see Teklehaymanot and Giday 2007).

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