



PERGAMON

Social Science & Medicine 56 (2003) 905–913

SOCIAL  
SCIENCE  
&  
MEDICINE

www.elsevier.com/locate/socscimed

## Disclosure of cancer diagnosis and prognosis in Northern Tanzania

Julian J. Harris<sup>a</sup>, John Shao<sup>b</sup>, Jeremy Sugarman<sup>c,\*</sup>

<sup>a</sup> Balliol College, Oxford University, Holywell Manor, Oxford OX1 3UH, UK

<sup>b</sup> Kilimanjaro Christian Medical Center, Tumaini University, Moshi, Tanzania

<sup>c</sup> Center for the Study of Medical Ethics and Humanities, Duke University Medical Center, Box 3040, 108 Steeley G. Mudd Building, Durham, NC 27710, USA

### Abstract

Whether to tell patients with cancer about their diagnoses and prognoses is a matter of great debate. While many argue the importance of giving this information to facilitate informed decision-making, others argue that this same information can extinguish hope. Although there is some evidence that disclosure of this information is now commonplace in many Northern and Western settings, there are very few data about this issue from resource-poor nations describing physicians' decision-making regarding whether to disclose this information. Using a combination of ethnographic and other qualitative methods including participant observation, semi-structured interviews, informal interviews, and a review of key documents in Northern Tanzania, we map some of the salient issues in this setting. Like their colleagues in many other parts of the world, Tanzanian physicians often withhold diagnostic and prognostic information from patients. In addition, however, to the cultural arguments often used to justify this practice, issues of treatment availability and patient poverty also influenced the physicians' disclosure practices. Expatriate and Tanzanian physicians practicing in Northern Tanzania often had different approaches to informing patients of their diagnoses and prognoses. Some Tanzanian physicians advocated the use of a "roundabout" approach to disclosure, arguing that it was more reflective of the normal mode of discourse in Tanzania than the more direct approach advocated by many of their expatriate colleagues. Expatriate physicians and some of their Tanzanian colleagues felt that such an indirect approach often left patients confused, or indeed, uninformed. © 2002 Elsevier Science Ltd. All rights reserved.

*Keywords:* Truth-telling; Cancer; Disclosure; Traditional medicine; Ethics; Tanzania

### Introduction

Whether to tell patients with cancer about their diagnoses and prognoses has received a great deal of attention in bioethics (Freedman, 1993; Suborne, 1992; Annas, 1992). While many argue that it is important to give patients this information so that they can make important decisions in an informed manner, others suggest that giving this sort of information can destroy hope. Moreover, based in part upon some broad cultural differences among those who hold one of these

alternative views, whether or not to tell the truth about diagnoses and prognoses in such situations has arguably come to symbolize the importance of cross-cultural differences in medical practice (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Beyene, 1992). However, the overwhelming majority of published empirical research on this topic comes from economically developed countries in North America, Europe, and Asia (Freedman, 1993; Dalla-Vorgia et al., 1992; Hoshino, 1995). Latin American and African approaches to disclosure have not been extensively reported in widely circulated peer-reviewed publications, and there is a paucity of data on this issue in resource-poor countries. Seeking to narrow that gap, this report draws upon research conducted in Northern Tanzania. The

\*Corresponding author. Tel.: +1-919-668-9000; fax: +1-919-668-1789.

E-mail address: sugar001@mc.duke.edu (J. Sugarman).

particular focus is on physicians' decisions concerning the disclosure of diagnostic, prognostic, and referral information that might potentially harm patients with cancer or their families and the effect of cultural, social, and economic factors on how this information is handled. As will be discussed, decisions concerning the use of this medical information also raise complex moral challenges regarding medical referrals for physicians in an impoverished nation who seek to minimize paternalistic behavior while balancing other ethical considerations.

## Background

The socio-cultural and economic context in which health care is delivered obviously shapes practices in the health care setting. Tanzania has a population of approximately 35 million, 31.7% of which is concentrated in urban areas. One of the poorest countries in Africa, the per capita gross domestic product (GDP) is US\$550. The infant mortality rate in Tanzania is 80.97 per thousand births, and the life expectancy is 45 years. Literacy rates are 79.4% for men and 56.8% for women (World Fact Book Data, 2000; World Bank Country Data, n.d.). With regards to religion, 45% of Tanzanians practice Christianity, 35% practice Islam, and 20% hold indigenous religious beliefs. Although Tanzania's national language is Kiswahili, most people have a mother tongue other than Kiswahili. In addition, English is the language of medical education and practice in Tanzania, and almost all medical training and staff interactions are conducted in English.

### *Kilimanjaro Christian Medical Center (KCMC)*

Situated at the foot of Mt. Kilimanjaro, Kilimanjaro Christian Medical Center (KCMC) is one of the largest research and teaching facilities in East Africa. KCMC is a complex institution with a unique medical culture (KCMC Annual Report, 1994). On the one hand, the hospital boasts modern diagnostic tools like a computerized tomography (CT) scanner, while on the other hand, physicians sometimes find themselves rationing basic antibiotic regimens. These contradictions are due in no small part to the whims of donors whose gifts depend as much on their particular interests as on the major health needs in the institution or the population that it serves.

In addition to the main hospital, the medical center includes more than ten schools and treatment centers in physiotherapy, medical records, nursing, medicine, and public health, among others. The hospital and its schools of allied health are now joined as Tumaini University. KCMC has a sizable foreign physician population that fluctuates between 10% and 25% of

the medical faculty. These physicians come primarily from the Scandinavian countries, Germany, the United Kingdom, and the United States, but there are also physicians from Asian countries and from other African nations. Many of the Tanzanian physicians at KCMC received their medical degrees outside of the country, adding further to the diversity of experiences represented by the medical faculty. Due to Tanzania's socialist political orientation following independence from Britain in 1963, these physicians studied in countries including Cuba, East Germany, the People's Republic of China, Romania, Turkey, and the Soviet Union. More recently, some of the physicians have done graduate work and fellowships in the United Kingdom, the United States, and in unified Germany.

## Methods

Without much published research about clinical ethics in East Africa,<sup>1</sup> a combination of ethnographic and other qualitative approaches were used, specifically participant observation and inscription, intensive, semi-structured interviews, informal interviews, and a review of key documents. These methods were selected in order to gain an understanding of the issues and experiences that prove challenging or particularly meaningful in this context (Emerson, Fretz, & Shaw, 1995).

During the course of this study, one of the authors (JH) spent over 250 h on the wards of the KCMC in Moshi, 50 h at Mawenzi District Hospital, and 14 h at Berega District Hospital in Morogoro Region in Central Tanzania, maintaining written records of observations. Following oral informed consent, intensive interviews (ranging from 40 min to 3 h) were conducted at all of these sites and were generally audiotaped at KCMC and Berega, but not so at Mawenzi. The interview guide was developed with the help of foreign and Tanzanian physicians familiar with medical practice in Northern Tanzania, and it was modified throughout the study as new themes emerged. Copious notes were taken in instances where taping was refused or seemed inappropriate.

The primary participants in this research were health care providers in Northern Tanzania (see Table 1).<sup>2</sup>

<sup>1</sup>Two notable exceptions are included among the references. See DelVecchio Good, Hunt, Munakata, & Kobayashi (1993), DelVecchio Good, Mwaikanbo, Amayo, & Machoki (1999) and Iliffe (1998).

<sup>2</sup>Two interviews were also conducted at Berega District Hospital located in Central Tanzania. While the results from these interviews cohered with the findings at KCMC and Mawenzi, the small sample size at the hospital, the limited catchment area, and the short amount of time spent in Berega by JH make us reluctant to extend our conclusions beyond Northern Tanzania.

Table 1  
Interview participants

	KCMC	Mawenzi	Berega
Specialists	6	1	1
Registrars/Medical officers	9	2	—
Interns	3	—	—
Assistant medical officers (AMOs)	—	5	1
AMO students	2	—	—
Clinical officers	—	3	—
Nurses	3	1	—
Total	23	12	2

Note: Specialists are physicians with an MD, BMch, or equivalent medical degree as well as specialized training as a resident or fellow in a medical specialty such as internal medicine, obstetrics and gynecology, or pediatrics. Registrars are generalist physicians with an MD, BMch, or equivalent medical degree who have not received formal training in a medical specialty. They are often assigned to a specialty such as pediatrics or internal medicine and receive informal training in that specialty on the job. Interns are students who have completed the academic portion of their medical training (i.e., an MD or BMch) and who are in the process of completing the apprenticeship portion. Assistant Medical Officers are former Clinical Officers who have completed an additional two-year course that prepares them to work as either assistants to registrars and specialists or as independent health care providers in some areas. Clinical Officers have completed their O-levels as well as one year of coursework and training in clinical medicine.

At KCMC and Mawenzi, these participants were drawn from the clinical staff in internal medicine, pediatrics, and obstetrics and gynecology. At KCMC, interviews were done with the majority of the senior medical staff (specialists, registrars, and interns) in these departments as well as a small sample of nurses and assistant medical officer students. At Mawenzi, much of the medical care is provided by assistant medical officers (AMOs), so participants were primarily drawn from this group. The physician and the AMO interviewed at Berega were the most senior members of the medical staff.

In order to identify recurring themes in the data, the constant comparative method of data analysis was used (Strauss & Corbin, 1990). This method requires the continuous review and comparison of notes from interviews and transcripts so that the course of the research is affected by emerging themes and categories that become apparent in the field. This process allowed for the detection of tensions in the data and further investigation of these tensions while there was still an opportunity to explore and participate in the setting (Glaser & Strauss, 1967).

## Results

While data were collected regarding a wide range of ethical challenges that arise in clinical practice in Tanzania, this report focuses on the issues related to the disclosure of cancer diagnoses and prognoses. Specifically, we focus on three domains that arose during analysis: (1) the use of the therapeutic privilege for patients with cancer, (2) approaches to disclosure of cancer diagnosis and prognosis, and (3) the relationship between morbidity, available therapeutic options, patient poverty, and referral issues.

### *Use of the therapeutic privilege*

Some of the physicians interviewed believed that only the relatives of elderly cancer patients should be told the diagnosis, especially if it is a terminal one, and that the family should make the decision about whether or not to tell the patient based upon their knowledge of his or her temperament and mental state. All of the foreign physicians and a few Tanzanian physicians found this practice, known as the therapeutic privilege, problematic because of their belief in patients' rights to know about their illnesses.

Foreign and Tanzanian physicians who support informing elderly patients of their diagnoses and prognoses offered anecdotes about patients thanking them for being the first person to be honest with them. One foreign doctor described the following:

Some of these cancer patients are laying around here, not knowing what's wrong with them, just knowing that they feel horrible. And when they see me, they sometimes ask me to explain their problem to them. I've been told before that I was the first person to really explain their illness to them.

A Tanzanian physician who disagreed with withholding diagnoses from elderly patients had this to say:

No, this thing about not telling old patients the diagnosis comes from old thinking. But you can't tell them directly at first, so you tell the relatives, and you let them help you decide how and what to tell the patient.

However, Tanzanian physicians also give anecdotes about elderly patients, who after being told of their terminal condition, gave up hope and died prematurely.

You try to tell them not to give up and that they aren't necessarily going to die right away, but some *wazee* [elderly men and women] lose all hope when they learn that they have cancer because they know that we don't have any medicine, and they just die that day or the next day.

Another physician had a somewhat different view:

With an *mzee* [an older man], we tell the relatives. [“Why?”] Because if they have cancer and they’re already *mzee*, and it’s a late stage, we think we should discharge them because we can’t do anything. We inform the close relatives because they can do more at home. They decide what to tell their *mzee* because they know him, they know if he can handle it.

All of the Tanzanian physicians interviewed supported a major role for the family in disclosure decision-making, but they differed in that some of the physicians were open to a familial decision to withhold disclosure completely while their colleagues relied on the family for assistance in disclosure. The physicians also expressed frustration over their inability to treat patients given the late stage at which most patients come to the hospital and the general lack of therapeutic options. Disclosure of a cancer diagnosis was seen as more ominous and stigmatized in the Northern Tanzanian setting than in wealthier countries in part because of patients’ awareness of the lack of therapeutic options and their associated loss of hope.

In Anglo-American settings, withholding diagnostic and prognostic information from patients has led to challenges from bioethicists concerned with the consequences of non-disclosure for patients and their families. With respect to these concerns, some of the Tanzanian physicians questioned their validity in Tanzania. That is, in addition to the now conventional, autonomy-based arguments for informing all patients of their condition and their treatment options, Anglo-American bioethicists sometimes give examples of the ways that patients may use the knowledge of their imminent death (Annas, 1992; Rodger, Simone, Simone, Simone, & Tanida, 1998). They argue that some patients may want to make peace with enemies, go on trips to memorable places or on long-desired vacations, or make decisions about the distribution of their assets.

Some Tanzanian physicians, familiar with these arguments, pointed out differences between the cultural and economic situations in the United States and Tanzania that reduce the significance of the consequences of non-disclosure in the latter context:

It’s not like in America where old people die alone, sometimes after having lived for years in nursing homes. We take care of our *wazee*, and they don’t have to worry about who to leave things to because they’re usually poor. They don’t have to worry about their children either because someone will take care of them.

Their practical justifications for the use of the therapeutic privilege included the following social, cultural, and economic considerations:

- (1) Cancer remains highly stigmatized in Tanzania due to varied cultural understandings of the disease’s etiology (e.g., it is sometimes viewed as a punishment or the result of a curse).
- (2) A lack of sufficient health resources in Tanzania severely limits treatment options for most patients diagnosed with cancer. Patients’ awareness of the lack of therapeutic options serves to strengthen the stigma associated with the disease.
- (3) The usually moribund status of patients who come to the hospital and are diagnosed with terminal illnesses in Tanzania limits their ability to live “new lives” after their diagnosis.
- (4) The desperate poverty of most patients limits their capacity to travel to cherished places and eliminates the need for complicated decisions about the distribution of property.
- (5) The closeness of families and communities eases the burden of decisions about the care of children or disabled relatives, as well as concerns about funeral arrangements.
- (6) Very strong family ties and the cherished role of elderly family members minimize the chances that the patient’s interests conflict with those of the family members.

While all of the physicians interviewed were generally aware of Western arguments for informing all patients of their disease status, regardless of age, many of the Tanzanian physicians challenged their consonance with the practices and beliefs of some of their patients and their patients’ families. They acknowledged that wealthy and more educated patients and relatives demonstrated increased interest in participating in treatment decisions and in learning and sharing information about terminally ill patients. This finding is consistent with data from the United States and other countries on the non-cultural factors that influence patients’ and families’ preferences for disclosure and their sense of empowerment in their interactions with physicians (Blackhall et al., 1995).

#### *Approaches to disclosure*

As described above, some Tanzanian physicians do not routinely inform elderly patients of a cancer diagnosis, particularly when the family stands opposed to disclosure. However, other Tanzanian physicians use variable criteria for determining whether and how much information to disclose to a particular patient. These physicians described their methods for evaluating the desire and ability of cancer patients to accept diagnostic and prognostic information. The approaches generally taken by Tanzanian physicians were characterized by what we term the *mzunguko* counseling method. *Mzunguko* is a Swahili term that means the act of going

around and around. When asked if this word appropriately described their approach to disclosure, the physicians confirmed its applicability. Some of the physicians use this method to determine when and how much information to give elderly cancer patients about their diagnoses and prognoses.

As is typical in many cultures, physicians in Tanzania begin by talking about things not at all related to the patient's illness, such as their families or their crops. Gradually they move the conversation to things indirectly related to the patient's diagnosis by asking the patient to describe in detail the symptoms that he or she has experienced. They also ask questions aimed at ascertaining the patient's mental competency and their likely responses to a terminal diagnosis of cancer. Step by step, these physicians move the conversation closer to the issue at hand. This process is never brief, and it may involve more than one session over the course of a few days in order to give patients the opportunity to gradually digest the information as their understanding of what is to come evolves. This extended process also provides the physician with more information with which to assess the patient's mental status and the possibility of suicidal ideations. Moreover, the *mzunguko* method enables physicians to gradually bridge the gap between the patients' knowledge and understanding of modern medicine and their cultural beliefs and interpretations of disease. It is important to underscore that the *mzunguko* method derives in large part from the dominant mode of interpersonal discourse in Tanzanian culture that includes extended greetings and indirect discussions of personal matters or problems before private or painful topics can be broached. Even a seriously ill or dying patient will respond to the question, "How are you?," with *mzuri kidogo*, which means, "only a little good", before responding to more specific questions about their pain and discomfort.

Some of the foreign physicians felt uncomfortable with their Tanzanian colleagues' roundabout approach, arguing that it leaves patients languishing and confused about their conditions during the process. These physicians shared stories of patients who told them that they felt as if they were the first clinician to be completely honest with them. Many of the Tanzanian physicians were similarly critical of the more direct counseling method used by their foreign colleagues. They argued that the expatriates' failure to understand Tanzanian cultural beliefs about disease and to adequately evaluate the scientific knowledge of patients led them to utilize an approach that often scares, confuses, and even angers patients who are unaccustomed to their less contextual, more direct approach:

Expatriates doctors are very direct. Maybe it's not just them. But society would prefer that they go around a bit. The problem is that our patients have a

different level of understanding. We should take more time before we get to the explanation of the problem. For our patients, it's not enough to say, "you have TB, HIV..." They don't even understand immunity. They need more time.

*Morbidity, availability of therapeutic options, patient poverty, and referral issues*

Tanzanian and expatriate physicians expressed concern over the major ethical challenges that they face when making referral decisions because of the morbidity and poverty that characterize much of their cancer patient population. Some of the physicians were very hesitant to refer their patients to the national cancer treatment facility, known informally as "Ocean Road,"<sup>3</sup> in the capital city of Dar es Salaam for the following reasons:

- (1) The journey itself lasts up to eight hours on sometimes-treacherous roads and often requires exhausting car and bus changes, which might be physically harmful to patients and prohibitively expensive for many families.
- (2) Successful treatment is unlikely. Even when the treatment is free, the relatives often incur large bills for travel, food, and lodging which may destroy them financially, ruin their children's hopes of attending school, or even wreak malnutrition and death on the family due to a lack of money for food.
- (3) Because of the expense of travel and residence, families are rarely able to send more than one or two relatives with the patient; in the case of a sick child, one parent usually accompanies the child, meaning that the other parent and the patient's siblings are unlikely to be present at the time of death.
- (4) If the patient dies in Dar es Salaam, the family also has to bear the burden of arranging for transport of the body back to their homeplace, an expense that can equal six to eight months' salary. If the patient was a child, the mother often carries the corpse tied to her back and repeats the grueling journey.

The physicians' responses to these considerations varied. Based upon what they know about the families' financial resources, some physicians do not refer their patients for further treatment, but rather send them home to die with their families. Others explain the high cost to the patients and their families and discourage the family from risking financial devastation by seeking

<sup>3</sup>The Ocean Road Cancer Institute has a formal, primarily academic affiliation with the Muhimbili University College of Health Sciences in Dar es Salaam.

further and likely ineffective treatment, but leave the decision up to the families. While approaches to resolving this situation vary, most physicians seem to make complicated decisions about patient referral only after group or departmental discussions with their physician colleagues. But even these discussions sometimes have led to decisions which might be regarded as paternalistic approaches to the patients and families' right to make their own choices concerning treatment options. As the physicians made clear, this situation is much more complicated in Tanzania than in wealthier countries because of the effects of financial devastation on families due to societal poverty and a relatively weak health care infrastructure.

Interestingly enough, both the Tanzanian and foreign physicians often encouraged the families of patients with cancer to take them home to die rather than to stay in the hospital. Aware that most patients probably sought the help of traditional healers before coming to the hospital and were likely to do so upon discharge, the Tanzanian physicians tried to make clear to patients' families the incurable nature of the patients' illnesses without discounting the potential psychological and spiritual benefits of seeking such counsel. Traditional healers often provide natural remedies for pain and nausea to cancer patients, so physical benefits could also be possible. The physicians' efforts to emphasize to families the incurable nature of the diseases result from their knowledge of the sometimes exorbitant prices charged by traditional healers which may be two or three times the fees paid to the physicians. However, the spiritual, mental, and physical support provided by these practitioners can play a major role in palliative care. Recognizing the value of this type of support for patients, physicians sometimes encourage them and their families to seek traditional care when the available medical therapies have nothing left to offer them. Tanzania's "Guiding Principles on Medical Ethics and Human Rights," which have yet to be fully promulgated, speak to the responsibility of physicians in their relationships with traditional practitioners, stating the following:

Physicians should inform patients if they have good reason to believe that the traditional treatment they are receiving is detrimental to their health. *But care should be taken not to exaggerate the proven benefits of orthodox medicine, and the patient should be helped to make an informed choice* [emphasis added]. Physicians should take interest in the activities of traditional healers and birth attendants and encourage them to adopt adequate hygienic and infection control measures (Medical Association of Tanzania, 1995).

The acknowledgment of the role that traditional healers and practitioners play in providing health care in Tanzania is critical to understanding patients' relation to the health care system. Some traditional healers selectively adopt Western practices and medicines as they see fit, combining these with traditional remedies, many of which provide patients with relief from their symptoms according to physicians interviewed in this study. So in withholding referral information from patients, physicians also consider the patient's quality of life under other forms of traditional care versus a death in a hospital that is typically far away from their families and traditional healers in their local communities.

Of note, many foreign physicians, initially opposed to the practice of withholding information concerning treatment options from patients, changed their minds with time as they began to see the impact of their decisions. They explained that by providing relatives with the slightest grain of hope that their *mzee* or child might survive if further treatment is sought, they have learned that they might be dooming the parents' other children to malnutrition, starvation, or a lack of educational opportunities because of the cost of seeking this treatment. In pediatrics, the effects of the parents' decision to seek further treatment for one of their children are felt full circle when two or three of the dead child's siblings are admitted to the hospital, sometimes moribund due to severe malnutrition. Poor education, unemployment, shabby dress, apparent difficulty in paying hospital bills, a paucity of visitors, and the knowledge of other children are generally taken as indications that parents are unable to bear the financial burden imposed by referral for expensive, usually futile, cancer treatments. Despite the pervasiveness of these concerns, some of the Tanzanian and foreign physicians argued that the final decision should always belong to the patient and the family and that judgments can *never* be made about a family's financial capabilities based on these characteristics, especially in light of the frequent provision of support offered by patients' churches, communities, and extended family members.

## Discussion

In understanding the findings of this study, it is important to keep certain factors in mind. First, the general sensitivity of physicians in this study to issues of patients' autonomy and the expressed desire of some patients for detailed information may not be generalizable to rural, less well-educated, or non-academic settings in Tanzania. Because of KCMC's cosmopolitan medical staff and its status as a major research institution, the physicians practicing there are likely to be far more familiar with the language and values of

Anglo-American bioethics than physicians in most other parts of the country. In addition, the Tanzanian medical faculty at KCMC tended to have a great deal of exposure to medical practices in foreign medical settings.

Because this was a qualitative study, the findings should not be taken to represent the views of all physicians in Tanzania or even at KCMC. Moreover, these data are derived primarily from interviews with medical personnel and do not include any systematic evaluation of patients' perspectives.<sup>4</sup> Nevertheless, a review of the limited literature in this area as well as conversations with Tanzanian and foreign physicians concerning these data suggest that they resonate with experiences of physicians who have practiced in Tanzania (DeVecchio Good et al., 1999).

In considering the results of this study, it is important to note that in many non-Anglo-American countries, the use of the therapeutic privilege is defended for cultural reasons. The data presented here cohere with the preponderance of cross-cultural and international literature on disclosure of medical information that suggests that many patients still prefer not to be informed directly of their diagnoses or prognoses or to participate in their treatment decisions (Blackhall et al., 1995; Dalla-Vorgia et al., 1992). Anglo-American authors recognize the right of patients, based on respect for their autonomy, to remain ignorant of their diagnosis and to cede decision-making authority to significant others (Freedman, 1993). However, the data presented in this report suggest that in addition to real or perceived patient preferences concerning disclosure, a lack of economic and therapeutic resources can also play a role in physicians' disclosure decisions, at least in Tanzania.

Despite this literature that endorses some exceptions to a general rule of directly giving patients information about their diagnoses and prognoses, there is a tendency, however, to allow the family to make the final disclosure decision for patients. None of the Tanzanian physicians in this study believed in withholding diagnoses from patients who explicitly asked to be told, but some of them did withhold terminal cancer diagnoses from elderly patients, relying instead on family members to make final disclosure decisions. The views and practices of these physicians reflected their disagreement with the requirement of disclosure of diagnosis and prognosis under the Anglo-American conception of respect for patient autonomy, with which most of them were familiar. It was clear that the conception of the patient as an atomistic individual whose interests and preferences might differ from or

conflict with those of family members lacks the cultural legitimacy in Tanzania that it has gained, to a certain extent, in the Anglo-American milieu. Instead, patients with cancer are viewed largely, though not exclusively, within the context of strong family and community relationships.

Also noteworthy, Tanzania's national guidelines for medical ethics (which, as mentioned above, have yet to be fully promulgated or accepted by Tanzanian physicians) explicitly assert the rights of patients to "receive relevant information about their own medical condition and its management" (Medical Association of Tanzania, 1995). Although these guidelines are based largely upon international covenants on human rights and international ethics guidelines, they do contain some references to the particular challenges to practice in resource-poor countries and to cultural differences that may complicate the application of recognized "universal" ethical principles under certain circumstances.<sup>5</sup> However, the data described here suggest that at least in certain cases, there is disagreement over the applicability of the guidelines' autonomy-based principles in Tanzanian culture.

While there is still disagreement over the decision to tell patients about their cancer diagnoses and prognoses, there was no discussion at all among Tanzanian or foreign participants about the breach of confidentiality involved in sharing the diagnosis of cancer with family members without the consent of the patient as being an ethical issue. Tanzania's medical ethics guidelines stress the importance of confidentiality, and physicians were sensitive to the complex issues surrounding confidentiality as it relates to sharing an HIV/AIDS diagnosis with sexual partners and family members. Such was not the case, however, for cancer. The fact that AIDS is a sexually transmitted disease and that it is more highly stigmatized than cancer may account for the participants' differential sensitivity to confidentiality related to disclosures about cancer and AIDS.

With regard to the stigma associated with cancer, and particularly its association with curses and the supernatural, it is important to recall that the explanations developed to account for diseases are not static; they evolve and are reinterpreted as new information is presented and evaluated. Public education about the causes of cancer was associated with a decrease in the stigma associated with the disease in the West, and increased efforts to educate people, particularly in rural

<sup>4</sup>Informal conversations were commonplace with patients and family members. However, since the goal in this first study was to focus on physician perspectives, these data were not collected or evaluated systematically.

<sup>5</sup>See the above section that discusses physicians' relationships to traditional healers in the Tanzanian context for an example of an ethical principle that reflects the cultural and economic climate in which medical care is delivered in Tanzania that might not be relevant or recognized in international guidelines on bioethics which focus primarily on research ethics.

parts of Tanzania, about the causes of cancer might be expected to have a similar effect.

Physicians' decisions to withhold diagnoses from potentially suicidal and depressed patients represent the classic ethical tensions between the principles of non-maleficence (not harming) and respect for autonomy. To the extent that physicians have strong reason to suspect suicide or severe depression, withholding the diagnosis temporarily may be justified. The model suggested by the *mzunguko* counseling method for determining when a patient may be ready to handle such information seems to be an appropriate one.

Although it is difficult to mediate the claims of the Tanzanian and expatriate physicians concerning direct versus *mzunguko*, or, round-about, approaches to counseling patients and disclosure, the claims of both groups are potentially valid, particularly given the diverse range of patients who seek treatment at KCMC. It may be the case that the roundabout counseling method used by Tanzanian physicians is more appropriate in general in Tanzanian culture since it may be in line with the preferences of patients. As long as this method eventually brings the patient to a sufficient level of understanding about their condition, it seems to be an acceptable and culturally appropriate approach to disclosure. Indeed, critiques of the direct approach to truth-telling in non-Western and Western contexts have led to the exploration and development of a range of indirect approaches that are more sensitive to the desire and readiness of patients to be informed or to remain ignorant of their diagnoses and prognoses while fulfilling physicians' fundamental responsibility to respect the patients' autonomy. These approaches also recognize the key role played by families in many contexts in patients' medical treatment and decision-making process (Beyene, 1992; Freedman, 1993; Spinsanti, 1992).

The relationship between the morbidity, availability of therapeutic options, poverty, and referral and disclosure merits further exploration in the Tanzanian context and internationally. Also worthy of comparative evaluation are the challenges that obtain in countries with an abundance of therapeutic options and more economic resources in general versus those that lack such therapeutic and economic resources (DelVecchio Good et al., 1999). As has been observed, the availability of new treatment options and the concomitant decrease in stigma played a major role in the shift of physicians' attitudes towards informing cancer patients of their diagnosis and, to a lesser extent, their prognosis in the United States (DelVecchio Good et al., 1993; Oken, 1979). Perhaps somewhat paradoxically, the ethical challenges faced by American physicians regarding disclosure of prognostic information are exacerbated by an abundance of therapeutic options because physicians worry that patients who are fully aware of

their prognosis will be less likely (and less capable physically) to undergo exhausting and sometimes painful treatment (DelVecchio Good et al., 1993).

While there is no uniformly enforced policy concerning referrals at KCMC, the physicians generally made complicated decisions about patient referral for advanced therapies only after group discussion. But even these discussions sometimes led to decisions that could be regarded as paternalistic violations of the patients' right to choose. However, this situation may be complicated in Tanzania because the effects of financial devastation are great due in part to a lack of social programs to meet such needs. As the expatriate physicians stated, dooming a mother's other children to malnutrition, starvation, or a lack of educational opportunities is an unfair but real consequence of giving some relatives even the slightest grain of hope of prolonging the patient's life.

This argument is compelling, but it does not render the principle of respect for autonomy invalid either philosophically or pragmatically, especially since it is difficult for physicians in a hospital to accurately ascertain the full extent of a family's resources. A number of physicians argued that judgments can never be made about a family's financial capabilities, especially in light of the frequent provision of support by wealthy relatives or their home church. In a study by Mary-Jo DelVecchio Good, this argument for disclosure of cancer diagnosis was also given by Tanzanian and Kenyan physicians practicing at the national medical centers in those countries with respect to discussion of HIV/AIDS treatment options which are available on a limited to basis to those who can afford them (DelVecchio Good et al., 1999).

These concerns and arguments notwithstanding, referral decisions for cancer treatment in Tanzania remains ethically complex, especially since the preponderance of ethical arguments in favor of disclosure fail to adequately speak to the challenges of physicians who feel directly responsible for the potential financial devastation caused by their referrals. The potential benefits to the family of such a referral can be a minimal chance of prolonging the life of a loved one and the peace of mind that comes from knowing that they tried their best. The potential harms to the sick child or relative include increased suffering due to the hardship of the journey and the cancer treatment itself, as well as the loss of a "good death" at home surrounded by loved ones and, perhaps, the spiritual and psychological care of a traditional healer. The potential harms to the family include financial insolvency, a resulting lack of educational opportunities for other children in the family, malnutrition, and even death. When faced with this decision, many parents and relatives, understandably unable or unwilling to see past their loved one's suffering, choose to take the risks and seek treatment



despite the best efforts of their physician to convince them otherwise.

Withholding referral information clearly constitutes a violation of the family's and the patient's autonomy rights and potentially the rights of the patient to life-saving treatment, depending on how one weighs their chance of survival after therapy versus death at home. However, the potential suffering of others, particularly the siblings of a sick child, raises concerns about justice that physicians may feel obliged to consider. As sympathetic as we may be to these concerns, it seems unreasonable to suggest that poor people's choices and desires to help sick loved ones should be truncated by wealthier, more powerful physicians, even when the potential risks to the family are great. In the short-term, physicians should augment their efforts to make clear to patients and family members the potential consequences of their choices. Meanwhile, increased examinations and conversations about the comparative benefits of palliative care, as it may be practiced with the aid of traditional healers, are desperately needed because of the lack of accessibility and availability of therapeutic options for terminal illnesses such as cancer and AIDS. In the long run, there should be continued efforts by Tanzanian physicians, health officials, and members of the international community to increase the access of people in Tanzania and other resource-poor countries to effective therapies for cancer and other life-threatening diseases.

### Acknowledgements

This research was funded in part by the Fogarty International Center, National Institutes of Health through the Minority International Research Training Program. Linda Lee Ph.D. helped with the study design. Research advice was provided in Tanzania by Gunther Lallinger, MD, MPH (Duke University) and Levina Msuya, MD (Tumaini University). Most importantly, the authors appreciate the willingness of the many health care providers to spend time sharing their thoughts regarding this important topic.

### References

Annas, G. (1992). Informed consent, cancer, and truth in prognosis. *New England Journal of Medicine*, 330, 223–225.  
 Beyene, Y. (1992). Cross-cultural medicine, a decade later: Medical disclosure and refugees—telling bad news to

Ethiopian patients. *Western Journal of Medicine*, 157(3), 328–332.  
 Blackhall, L., Murphy, S., Frank, G., Michel, V., & Azen, S. (1995). Ethnicity and attitudes toward patient autonomy. *Journal of the American Medical Association*, 274, 820–825.  
 Dalla-Vorgia, P., Katsouyanni, K., Garanis, T. N., Touloumi, G., Drogari, P., & Koutselinis, A. (1992). Attitudes of a Mediterranean population to the truth-telling issue. *Journal of Medical Ethics*, 18, 67–74.  
 DelVecchio Good, M. J., Mwaikanbo, E., Amayo, E., & Machoki, J. M. (1999). Clinical realities and moral dilemmas: Contrasting perspectives from academic medicine in Kenya, Tanzania, and America. *Daedalus*, 128(4), 167–196.  
 DelVecchio Good, M. J., Hunt, L., Munakata, T., & Kobayashi, Y. (1993). A comparative analysis of the culture of biomedicine: Disclosure and consequences for treatment in the practice of oncology. In P. Conrad, & E. Gallagher (Eds.), *Health and healthcare in developing countries*. Philadelphia: Temple University Press.  
 Emerson, R., Fretz, R., & Shaw, L. (1995). *Writing ethnographic fieldnotes*. Chicago: University of Chicago Press.  
 Freedman, B. (1993). Offering truth: One ethical approach to the uninformed cancer patient. *Archives of Internal Medicine*, 153(5), 572–576.  
 Glaser, B., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.  
 Hoshino, K. (1995). Autonomous decision making and Japanese tradition. *Cambridge Quarterly of Healthcare Ethics*, 4(1), 71–74.  
 Iliffe, J. (1998). *East African doctors: A history of the modern profession*. New York: Cambridge University Press.  
 Kilimanjaro Christian Medical Centre. (1994). *Annual report, facts & figures*. Moshi, Tanzania.  
 Medical Association of Tanzania. (1995). Medical ethics and human rights guiding principles.  
 Oken, D. (1979). Changing attitudes towards telling the cancer patient. *Journal of the American Medical Association*, 241, 897–900.  
 Rodger, C., Simone, C., Simone, N., Simone, C. B., & Tanida, N. (1998). Do we always need to tell patients the truth? *Lancet*, 352, 1787.  
 Spinsanti, S. (1992). Obtaining informed consent from the family: A horizon for clinical ethics. *Journal of Clinical Ethics*, 3, 191.  
 Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, California: Sage.  
 Suborne, A. (1992). Truth telling to the patient [letter]. *Journal of the American Medical Association*, 268, 1661–1662.  
 World Bank Country Data (n.d.). <http://www.worldbank.org/data/countrydata/countrydata.html>  
 World Fact Book Data. (2000). <http://www.odci.gov/cia/publications/factbook/geos/tz.html>