Truth-Telling and Cancer Diagnoses: Physician Attitudes and Practices in Qatar

PABLO RODRIGUEZ DEL POZO,^a JOSEPH J. FINS,^e ISMAIL HELMY,^d RIM EL CHAKI,^c TAREK EL SHAZLY,^c DEENA WAFARADI,^c ZIYAD MAHFOUD^b

^aDivision of Medical Ethics, and ^bDepartment of Public Health and Department of Global and Public Health, ^cWeill Cornell Medical College in Qatar, Doha, Qatar; ^dDepartment of Medical Education, Hamad Medical Corporation, Doha, Qatar; ^eDivision of Medical Ethics, Weill Cornell Medical College, New York, New York, USA

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LEARNING OBJECTIVES

After completing this course, the reader will be able to:

1. Compare physician-stated and actual disclosure practices with respect to cancer diagnoses.
2. Identify variables that influence physician truth-telling practices with respect to cancer diagnoses.

CME

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ABSTRACT

There is limited information regarding physicians' attitudes toward revealing cancer diagnoses to patients in the Arab world. Using a questionnaire informed by a seminal study carried out by Oken in 1961, our research sought to determine present-day disclosure practices in Qatar, identify physician sociodemographic variables associated with truth-telling, and outline trends related to future practice.

A sample of 131 physicians was polled. Although nearly 90% of doctors said they would inform cancer patients of their diagnosis, ~66% of respondents stated that they made exceptions to their policy, depending on patient characteristics. These data suggest that clinical practices are somewhat discordant on professed beliefs about the ethical propriety of disclosure. *The Oncologist* 2012;17:1469–1474

INTRODUCTION

Over the past half century, evolving medical ethics has identified the patient's right to know his or her diagnosis and the physician's reciprocal duty of disclosure as key elements of the informed consent process. But what began in the U.S. and has taken deep cultural roots in medical practice there, has not been universally assimilated into medical practices and cultural norms across the globe. In this paper, we review the historical evolution of truth-telling with an emphasis on this evolving practice in the Arabic-speaking world. To that end, we offer an empirical study—and ethical analysis—of current attitudes of physicians practicing in Qatar with specific reference to the disclosure of a cancer diagnosis.

BACKGROUND

“No problem is more vexing than the decision about what to tell the cancer patient,” writes Oken at the start of his groundbreaking 1961 article in the *Journal of the American Medical Association* on how much to say to patients diagnosed with cancer [1]. In Oken's study, the inspiration for subsequent studies on truth-telling, the majority of physicians (88%) agreed not to inform a cancer patient of his or her diagnosis. Eighteen years later, Novack and others replicated Oken's study and found a radical change in professed beliefs: 98% of physicians said that their general policy was to tell patients their diagnosis [2]. This divergence underscored how physicians' personal policies had transformed over time, going from a “practically *never* inform” policy in 1961 to a “nearly *always* inform” policy in 1979. In the brief course of two decades, there was a sea change in how doctors broke bad news.

This change has been attributed to the social transformation of the 1960s and 1970s, decades in which a broad questioning of hierarchies and the U.S. civil rights movement fostered a greater concern for patient self-determination and, with it, the notion of a patient's need to know his or her diagnosis so as to make informed choices. These evolving norms coalesced in legal standards for disclosure [3], a trend fostered by an enhanced ability to detect and treat many forms of cancer [4].

Despite a radical change in practice in the U.S., this trend has been neither universal nor temporally concordant across the globe, reflecting differing cultural norms. A cross-European study concluded, in 1993, that doctors from northern Europe disclosed diagnoses to patients and families almost without exception, whereas southern and eastern European doctors preferred not to disclose any information [5]. Researchers in Norway showed that the great majority of physicians fully informed their cancer patients of their diagnosis [6]. Scholars such as the Spanish bioethicist and medical historian Diego Gracia Guillen have traced such differences to the extent of the northward expansion of the Roman Empire and the subsequent divide between the communitarianism of southern Europe and the individualism of northern Europe [7]. An example of this variance is seen in Gracia's native Spain, where only 30% of physicians informed cancer patients of their diagnosis according to a study by Rodríguez-Marín and others published in 1996 [8]. Cases of intentional nondisclosure—indeed

of ingenious schemes to deceive patients—have been reported from Spain [9], indicating, at the very least, the incomplete penetration of North American norms relating to truth-telling.

DISCLOSURE IN THE ARAB WORLD

There is rather limited information on physicians' attitudes toward informing patients of cancer diagnoses in the Arabic-speaking and Muslim world, although there seems to be a mismatch between what patients prefer and what doctors and families actually do. Al-Amri showed, in 2009, that an overwhelming majority of Saudi nationals wanted to be fully informed of their cancer diagnosis [10], whereas Younge et al. [11] reported that consent for cancer treatment is usually given by a family member, rather than by the patient, and that families and doctors agree that this approach avoids upsetting the patient.

Studies consistently highlight that sociocultural elements in the Arab and Muslim world play a role in determining how much—or how little—information should be shared with a patient diagnosed with cancer. A study on cancer and truth-telling in Lebanon showed that 47% of physicians disclosed the truth to cancer patients whereas 53% did not [12]. An editorial article from Iran asserted that there were positive benefits, such as the prevention of psychological harm, when a terminal diagnosis is withheld from the patient [13].

OBJECTIVES

The primary objective of this study was to assess physicians' policies and practices toward informing patients of their cancer diagnosis. We also aimed at exploring whether or not physicians' disclosure policies and practices are associated with their sociodemographic, religious, cultural, and educational backgrounds.

METHODS

The study was cross-sectional in nature, whereby a convenience sample of 131 physicians from nine different Hamad Medical Corporation (HMC) hospitals and outpatient centers were given the study instrument to complete. HMC is the de facto national health service of Qatar. It provides a comprehensive spectrum of health care services to 100% of Qatar's 1.7 million national and foreign residents. The corporation consists of a conglomerate of seven hospitals and 22 satellite outpatient centers, staffed by 2,685 physicians representing 46 medical and surgical specialties and subspecialties [14].

Physicians were contacted during departmental meetings or individually in their offices. Although all physicians in the sample could theoretically have cancer patients in their practices, only 13% were oncologists. The time period for data collection was May to June 2011.

The study instrument was developed using the basic structure of Oken [1] and later Novack et al. [2]. In addition to the information collected by those studies, our study added questions to capture cultural and religious factors that might be associated with a respondent's attitudes and practices. The instrument can be found in supplemental online data.

An earlier version of the questionnaire was piloted for clar-

ity and relevance on 10 doctors with faculty appointments at the Weill Cornell Medical College in Qatar (WCMC-Q). Several edits were made. Data from the pilot test were not used for this analysis. There was no need to translate the instrument to Arabic because all physicians were fluent in English, which is the working language of medicine in Qatar. The study was confidential, voluntary, and anonymous. It was self-administered. The institutional review boards of WCMC-Q and HMC approved the study.

Statistical Analysis

Sample characteristics were summarized using means and standard deviations for numerical variables such as age and frequency distributions for categorical variables such as policy and gender. The prevalence of physicians who usually tell their patients about their cancer diagnosis was computed along with its 95% confidence interval (CI). Moreover, we computed the prevalence and 95% CI of those who, in rare cases, make exceptions to their stated policy and tested whether or not making exceptions was different between those who usually tell and those who do not tell using Fisher's exact test. Rationales for making exceptions were summarized using frequency distributions (Table 1). Associations between doctors' policies and demographic, religious, cultural, and educational variables were evaluated using the χ^2 test or Fisher's exact test for categorical variables and the Wilcoxon rank sum test for numeric variables (Table 2). Doctors' attitudes toward truth-telling to patients and future research in the field were summarized using frequency distributions (Table 3). All analyses were done using IBM SPSS, version 19 (SPSS Inc., Chicago, IL). Significance was set at the 0.05 level.

RESULTS

All 131 physicians surveyed agreed to participate, for a 100% participation rate. The average age of participants was 39.3 ± 11.5 years (range, 23–68 years). The majority were male (54.7%). The vast majority were Arabs (85.2%) and Muslims (90.7%). Most of the physicians considered themselves “fairly religious” (78.6%), whereas 19% considered themselves “very religious” and 2.4% considered themselves “not religious.”

Regarding specialty, 13.0% were oncologists or hematologists, 14.5% were internists, 16.8% were general practitioners, 11.5% were pediatricians, 13.7% were obstetrician-gynecologists, 7.6% were surgeons, 15.3% had another specialty, and 7.6% had an undeclared specialty. Nearly one in five participants (19.5%) received their medical training in a non-Arab country. Most of the doctors in this study (61.3%) had practiced in Qatar for the majority of their career.

With regard to the central question of truth-telling, a large majority of respondents (88.5%; 95% CI, 81.8%–93.4%) reported that their usual policy was to tell patients of their cancer diagnosis but, notably, a majority also revealed that they would make exceptions in rare cases (66.4%; 95% CI, 57.6%–74.4%). The percentage of physicians who would make exceptions to their policy was significantly higher among physicians whose usual policy was to tell (74.3%) than among those whose usual policy was not to tell (23.1%). Moreover, there

Table 1. Doctors' policy regarding telling a patient about his or her cancer diagnosis

Question	n (%)
Usual policy about telling patient that they have cancer	
Tell	116 (88.5%)
Do not tell	13 (9.9%)
No answer	2 (1.5%)
How often do you make exceptions to your rule?	
Never	39 (29.8%)
Very rarely	87 (66.4%)
No answer	5 (3.8%)
What factors are important when telling a patient? ^a	
Emotional stability	71 (74.0%)
Age	66 (68.8%)
Intelligence	65 (67.7%)
Patient wish to be told	58 (60.4%)
Medical sophistication	49 (51.0%)
Acceptance of recommended therapy	49 (51.0%)
Relatives wish (about telling the patient)	45 (46.9%)
Patient is a physician	43 (44.8%)
Length of survival	39 (40.6%)
Social status	35 (36.5%)
Sex of patient	25 (26.0%)
Religion of patient	24 (25.0%)
Patient asking no question	14 (14.5%)
Has your policy changed from before?	
Yes	44 (33.6%)
No	85 (64.9%)
No answer	2 (1.5%)
How likely do you think that your policy will change in the future?	
No possibility	12 (9.2%)
Very unlikely	22 (16.8%)
Unlikely	29 (22.1%)
Probably	53 (40.5%)
Certainly	11 (8.4%)
No answer	4 (3.1%)

^aOnly among those who make exceptions and physician can have more than one answer.

was fluidity in their views. A third of respondents said that their policy had changed over the years and about half thought that their policy would probably or certainly change in the future, although they did not specify whether the direction would be more forthcoming or not.

The most frequently reported factors that physicians would take into account when making an exception to truth-telling were the patient's emotional stability (74.0%), age (68.8%), and perceived intelligence (67.7%). To a lesser extent, the patient's sex (26%) and religion (25%) were still considered when making an exception to the truth-telling practice.

Variable	Policy to tell (<i>n</i> = 116)	Policy not to tell (<i>n</i> = 13)	<i>p</i> -value
Mean age (standard deviation)	38.8 (11.4)	42.6 (12.6)	.310
Gender, <i>n</i> (%)			.563
Male	60 (88.2%)	8 (11.8%)	
Female	53 (91.4%)	5 (8.6%)	
Ethnicity, <i>n</i> (%)			.214
Arab	94 (87.9%)	13 (12.1%)	
Non-Arab	19 (100.0%)	0 (0.0%)	
Religion, <i>n</i> (%)			.999
Muslim	103 (88.8%)	13 (11.2%)	
Christian	7 (100.0%)	0 (0.0%)	
Other	4 (100.0%)	0 (0.0%)	
Religiousness, <i>n</i> (%)			.775
Very religious	21 (87.5%)	3 (12.5%)	
Fairly religious	88 (89.8%)	10 (10.2%)	
Not religious	2 (100.0%)	0 (0.0%)	
Country of origin			.217
Arab country	90 (87.4%)	13 (12.6%)	
Non-Arab country (U.S., U.K., India, Pakistan, and Eritrea)	19 (100.0%)	0 (0.0%)	
Country where medical degree obtained			.457
Arab country	87 (88.8%)	11 (11.2%)	
Non-Arab country (Australia, Hungary, India, Pakistan, Italy, Iran, Ireland, U.S., U.K.)	23 (95.8%)	1 (4.2%)	
Specialty			.267
General practice	18 (81.8%)	4 (18.2%)	
Internal medicine	16 (84.2%)	3 (15.8%)	
Oncology/hematology	17 (100.0%)	0 (0.0%)	
Pediatrics	12 (80.0%)	3 (20.0%)	
Obstetrics and gynecology	17 (94.4%)	1 (5.6%)	
Surgery	10 (100.0%)	0 (0.0%)	
Other	18 (81.8%)	1 (5.3%)	
Mean yrs as physician (standard deviation)	13.8 (10.9)	17.8 (13.5)	.292

In this rather homogeneous sample, there were no clear associations between the propensity to disclose and sociodemographic or cultural or religious variables (Table 2). Nevertheless, some trends were observed. For example, we noticed that only Arab and Muslim doctors, or doctors who had studied in the region, reported that their usual policy was to not tell. Moreover, although not statistically significant, physicians who reported that their usual policy was to tell patients about their cancer diagnosis were, on average, 5 years younger than their nondisclosing counterparts.

As shown in Table 3, a majority (71.0%) of participants responded with “yes” to the question of whether or not it is more difficult to inform a cancer patient of his or her diagnosis than a patient who has another disease with the same prognosis. One

in four physicians reported that they would prefer that patients learn of their diagnosis from “other people.”

When asked whether or not they would like to be informed of their diagnosis if they were the patient, most doctors (88.5%) responded that they would want to know the truth.

The vast majority of physicians (90.8%) felt that more research should be carried out in this area of biomedical ethics to guide practice. The majority responded that their policy might change (70.2%) based on the results of empirical research.

Limitations

Because this is a cross-sectional study, no direction of the association found can be claimed definite. The sample was convenient in nature, yet diverse in terms of demographics and

Table 3. Physicians' attitudes toward disclosure of a cancer diagnosis

Question ^a	n (%)
More difficult to convey cancer versus noncancer diagnosis with same prognosis?	
Yes	93 (71.0%)
No	33 (25.2%)
No answer	5 (3.8%)
Prefer patients learn diagnosis from nonphysician or other source?	
Yes	33 (25.2%)
No	94 (71.8%)
No answer	4 (3.1%)
Desire for knowledge of own cancer diagnosis?	
Yes	116 (88.5%)
No	12 (9.2%)
No answer	3 (2.3%)
Continue research about truth-telling?	
Yes	119 (90.8%)
No	9 (6.9%)
No answer	3 (2.3%)
Influence of research results on future policy?	
Yes	92 (70.2%)
No	35 (26.7%)
Maybe	1 (0.8%)
No answer	3 (2.3%)

^aFor clarity, questions are shortened in table.

representative in terms of ethnicity. The size of the sample might have limited our ability to assert the observed trends with statistical significance. However, this is the first study of its kind in Qatar, and possibly the Gulf region, and although more research is needed in this area, the results address the main research questions. The study also establishes baseline values for current practices in Qatar, which could allow for future longitudinal studies of truth-telling and disclosure.

DISCUSSION

It is clear from the study that most doctors in Qatar support truth-telling when there is a cancer diagnosis; their practices are all statistically similar and the majority declare a policy of full disclosure. However, this policy seems to be elastic and contingent upon circumstances. We note that 74.3% of respondents stated that they would make exceptions to their general norm of disclosure, although they asserted that this would only happen in *very rare* situations, a situation which itself is ill-defined and open to interpretation. This suggests that the stated views may not equate with actual practice, a point substantiated by the fact that ~50% of doctors responded that their

stance on truth-telling was likely to change or might certainly change in the future.

Our study suggests that, even though most doctors believe as a matter of principle that patients should be informed, in reality they make room for exceptions. These exceptions, which could undermine the principle, warrant further study and need to be understood in a cultural context. This is especially salient because of physicians' willingness to change policy depending upon circumstance. This speaks to the frailty of the norm.

Disclosure policy is, thus, still a shifting issue for most doctors. This may be why there are generally no fixed institutional policies about truth-telling and why doctors seem open to embracing new norms.

Nevertheless, we found it notable that, despite the above-mentioned uncertainties—or perhaps because of them—most doctors believe that patients should learn about their diagnosis from a physician and not from someone else. This indicates to us that doctors in Qatar accept this professional responsibility and appreciate that there may be adverse consequences when disclosure is left in the hands of nonphysicians. It may also call attention to the fact that physicians in Qatar underestimate the role of allied professions—psychology and social work—in patient care, a topic worthy of further exploration.

Exceptions to truth-telling to patients were less prompted by the patient's gender (26%), religion (25%), and social status (36.5%) than by his or her emotional stability (74%), age (68.8%), and intelligence (67.7%). In addition, about half of the physicians who made exceptions took into consideration the wishes and preferences of relatives, which may be a result of the nature of familial ties in the Arab region. In other words, the context of care seems to come into play. Doctors define a particular policy for each case, depending on contextual information. This pattern is consistent with what two of us (P.R.P. and J.J.F.) have discussed elsewhere, in the sense that in so-called high-context cultures, such as those of the Mediterranean basin and the Arabic-speaking countries, individuals are highly sensitive to contextual clues [15, 16].

Although there were no associations between the physicians' policy and their sociodemographic and cultural backgrounds, we noted that 100% of non-Arab and non-Muslim doctors had a policy of always telling patients of their cancer diagnosis, whereas >11% of Arab and Muslim doctors were categorical about a nondisclosure policy. Conversely, most physicians who attended medical school in non-Arab countries—except for one outlier—favored full disclosure. More data are needed to confirm this putative correlation between education and beliefs. Although our sample size did not reach statistical significance, our findings could indicate that cultural background and education play a role in shaping disclosure policies. More research is needed to fully understand a possible correlation.

The data suggest that relative youth correlates with a more forthcoming attitude toward disclosure. This may reflect a generational shift in practice or perhaps be covariant with the greater likelihood that young physicians were trained abroad.

Yet, irrespective of their background and professed be-

liefs, a high percentage of physicians would make exceptions to their generally stated disclosure norm. That 74.3% of physicians reported resorting to what in the West is described as the “therapeutic privilege,” that is, taking the prerogative of nondisclosure, shows the fragility of the norm in this context. We do not have data on the percentage of cases for which the therapeutic privilege was actually invoked or on the specific circumstances. This could be the object of a prospective analysis.

CONCLUSIONS

Despite all the progress in cancer therapy and its increasingly favorable prognosis in many cases, informing patients about their diagnosis of cancer is still vexing for many doctors. But no matter how challenging, doctors in Qatar report that informing patients of this diagnosis is their responsibility and one they are willing to assume.

Our study provides insight into this process in Qatar and reveals that doctors, more or less independently of their nationality, religion, or place of study, are in principle all equally inclined to inform patients about their diagnosis of cancer. But importantly, we also found that physicians are ready to adjust their policies by making exceptions on a case-by-case, patient-by-patient basis.

Notably, the majority of doctors seem to feel that their policy on informing patients of their diagnosis of cancer could change in the future, depending on what research shows. This is a welcome development and shows the openness of the Qa-

tari medical community to empirical evidence and the evolving knowledge of practice norms.

Knowledge from empirical studies in bioethics can inform strategies aimed at enhancing doctor–patient communication in Qatar, an essential step in furthering patient rights in a culturally sensitive fashion and in providing better care for patients from this region in an increasingly globalized world.

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AUTHOR CONTRIBUTIONS

Conception/Design: Pablo Rodriguez del Pozo, Joseph J. Fins, Ziyad Mahfoud
Provision of study material or patients: Ismail Helmy

Collection and/or assembly of data: Pablo Rodriguez del Pozo, Rim El Chaki, Tarek El Shazly, Deena Wafadari, Ziyad Mahfoud

Data analysis and interpretation: Pablo Rodriguez del Pozo, Joseph J. Fins, Ismail Helmy, Rim El Chaki, Tarek El Shazly, Deena Wafadari, Ziyad Mahfoud

Manuscript writing: Pablo Rodriguez del Pozo, Joseph J. Fins, Ismail Helmy, Rim El Chaki, Tarek El Shazly, Deena Wafadari, Ziyad Mahfoud

Final approval of manuscript: Pablo Rodriguez del Pozo, Joseph J. Fins, Ismail Helmy, Rim El Chaki, Tarek El Shazly, Deena Wafadari, Ziyad Mahfoud

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