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ORIGINAL RESEARCH

Attitudes of cancer patients and their families toward disclosure of cancer diagnosis in Saudi Arabia: a Middle Eastern population example

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Objectives: Particularly in the Middle East, few studies have explored the attitude of cancer patients and their families toward cancer diagnosis disclosure (CDD). This study was conducted to investigate the preference and attitude of a sample of cancer patients and their families in Saudi Arabia toward CDD.

Methods: We constructed a questionnaire based on previous studies. The questionnaire assessed preference and attitude toward CDD. Participants were recruited from the King Abdullah Medical City, which has one of the largest cancer centers in Saudi Arabia.

Results: Three hundred and four cancer patients and 277 of their family members participated in the study. The patient group preferred CDD more than the family group (82.6% vs 75.3%, $P<0.05$). This preference is especially more evident toward disclosure of detailed cancer information (status, prognosis, and treatment) (83.6% vs 59.9%, $P<0.001$). In a binary logistic regression, factors associated with preference toward CDD included having information about cancer (odds ratio [OR] 1.8; 95% confidence interval [CI], 1.15–2.84) and being employed (OR, 1.77; 95% CI, 1–2.82) while being from the patient group was the only factor associated with preference toward detailed cancer information (OR, 3.25; 95% CI, 2.11–5.05). In terms of patient reaction after CDD, "fear" was the attitude expected by the family group more than the patient group (56.3% vs 70.4%, $P<0.001$) while "acceptance" was the attitude anticipated by the patient group more than the family group (38% vs 15.2%, $P<0.001$).

Conclusion: Patients preferred CDD and disclosure of related information, while their families were more inclined toward scarce disclosure. Family members seem to experience negative attitudes more than the patients themselves.

Keywords: oncology, disclosure, family, caregiver, culture, Muslim, perception, preference, communication, bad news, patient-centered

Background

For many patients, including cancer patients, preserving patient autonomy is a central component of the patient-centered model.[1] The model focuses on active patient participation, values, and needs in order to improve the overall quality of care. It presents a shift from a paternalistic approach in clinical management, to an approach that ensures mutual decision-making between patients and physicians.[2] When the patient-centered model has been implemented, studies found improvement in the quality of health care, decrease in costs, and greater satisfaction for health care providers and patients.[3,4]

Levels of patient autonomy vary significantly around the world. For example, in Eastern cultures, health care providers involve the family in the decision-making process, often without the patient's consent. Indeed, some patients may know less

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than their family about their own diagnoses, procedures, and planned interventions.[5]

In Saudi Arabia, a country with a Middle Eastern culture and a predominately Muslim population, a number of studies found that oncologists often initially disclosed cancer information to the patient's family, and that the family would then take over decision-making in terms of procedure and medical interventions. However, on the contrary, these studies also found that almost all cancer patients preferred self-disclosure of cancer as well as more active participation in medical decision-making.[6–10]

Although previous studies in Saudi Arabia examined the attitude of patients toward cancer diagnosis disclosure (CDD), there is a paucity of research exploring family perspectives toward CDD. To our knowledge, there is no study that has explored important aspects related to attitudes of patients and families toward CDD in Saudi Arabia (eg, reasons for disclosure/nondisclosure, patient reaction to CDD, and factors to accept CDD). Our study aims to fill this gap in the literature by examining the perspectives of patients and their families toward CDD, and exploring the factors that influence their attitudes.

Methods

Participants and procedures

The present study involves a cross-sectional survey of cancer patients and their families. Convenience sampling was used. Inclusion criteria were cancer patients aged 18 or above accompanied by family member, based at the Oncology Clinic of the King Abdullah Medical City. Cancer in patients and their accompanied family members were also included in the study. At the time of surveying, the medical city housed 550 beds, providing tertiary care to patients from across Saudi Arabia, although patients were largely from the western coast of the country. All participants in the study were Muslims. Exclusion criteria were lack of capacity to consent and refusal of participation.

In total, 581 individuals (304 cancer patients and 277 family members) were involved in the study. Each individual was given information explaining the study and was asked to verbally consent to participation. Those who accepted were then interviewed by a member of the research team via direct questioning. Patients were first interviewed apart from their families in the waiting area of the oncology outpatient clinic, or in their rooms if they were in patients. Families were then subsequently interviewed by the same research member separately. Twenty-seven family members refused to participate. Reasons for nonparticipation included interruptions due to patient appointments or lack of interest.

Measurements

The study involved the development of a questionnaire examining the attitudes of patients and their family members. The questionnaire was adopted from Farhat et al,[11] who attempted to capture religious and social factors influencing decision-making. The questionnaire gathered information on the following: demographic information (age, sex, education level, relationship to patient, and employment status); clinical information (primary cancer type, disease stage, and awareness of cancer diagnosis); attitude toward CDD and factors influencing decision-making, which encompassed the first 16 questions based on the questionnaire from Farhat et al.[11] This final point includes information pertaining to preference of CDD, reasons for disclosure and nondisclosure, knowledge about cancer, expected patient reaction when learning about diagnosis, and factors that may help in accepting cancer diagnosis.

Statistical analysis

The study employed descriptive statistics to describe the general demographics of patients and family members. We used an unpaired Student's *t*-test or χ^2 test to determine significant differences between the patient and family group. In addition, we used binary logistic regression analysis to estimate the odds ratio for three dependent variables: 1) preference of CDD, 2) preference of detailed cancer-related information, and 3) timing of CDD (before or after treatment). The significant level was set at $P<0.05$. IBM SPSS Statistics 21.0 (IBM Corporation, Armonk, NY, USA) was used for all statistical analyses.

Results

Sample characteristics

Five hundred and eighty-one subjects participated in this study (304 patients and 277 family members). Table 1 shows the characteristics of the respondents. The patient group consisted of more females ($P<0.001$), and subjects were older ($P<0.001$), less educated ($P<0.001$), and more unemployed ($P<0.001$) compared to the family group. The patient group were accompanied by children more often than other types of family members ($P<0.001$), and the majority of the patient group (86.27%) knew about the diagnosis prior to treatment.

Differences in attitudes toward CDD

Having knowledge about cancer was reported by 54.2% of the patients and 59.5% of their family members. Their sources of information were the media (26.3% and 33.7%, respectively),

Table 1 The characteristics of the subjects

Characteristics	Patient group, N=304	Family group, N=277	*P*-value
Age			<0.001
Mean	48.3	36.51	
SD	15.3	12.5	
Gender			<0.001
Male	114 (37.6%)	129 (53.1%)	
Female	189 (62.4%)	114 (46.9%)	
Education			<0.001
Did not complete high school	152 (50.2%)	59 (24.3%)	
Completed high school	151 (49.8%)	184 (75.7%)	
Employment			<0.001
Employed	63 (20.8%)	108 (44.4%)	
Unemployed	240 (79.2%)	135 (55.6%)	
Relation to patient			<0.001
Father	–	10 (5.6%)	
Mother	–	22 (12.4%)	
Husband or wife	–	32 (18.1%)	
Son or daughter	–	74 (41.8%)	
Brother or sister	–	21 (11.9%)	
Other	–	18 (10.2%)	
Time of knowing the diagnosis			
Before treatment	245 (86.27%)	–	
During treatment	27 (9.51%)	–	
After treatment	12 (4.23%)	–	
Type of cancer			
Breast cancer	68 (22.4%)	–	
Lymphoid cancer	56 (18.4%)	–	
Gastrointestinal cancer	64 (21.1%)	–	
Genitourinary cancer	31 (10.2%)	–	
Lung cancer	16 (5.26%)	–	
Central nervous system cancer	9 (2.96%)	–	
Thyroid cancer	7 (2.30%)	–	
Other types	32 (10.5%)	–	
Patient does not know	21 (6.91%)	–	
Stage of cancer			
Metastasized	57 (19.86%)	–	
Not metastasized	163 (56.79%)	–	
Patient does not know	67 (23.34%)	–	

physicians (28.6% and 18.8%), personal experience (30.6% and 1.4%), and family experience (6.6% and 25%).

The patient group was more likely to respond that the patient should be informed about the cancer diagnosis than the family group (82.6% vs 75.3%, $P<0.05$; Figure 1); and more likely to respond that the patient should be informed about the details of the cancer status (cancer stage, prognosis, and management) (83.6% vs 59.9%, $P<0.001$; Figure 1). The reasons that participants gave for answering "Yes" or "No" to the questions of disclosure are detailed in Table 2.

The patient group was more likely to respond that the patient should be informed about the cancer diagnosis prior to the start of treatment than the family group (72.9% vs 64%, $P<0.05$; Figure 1). In addition, the patient group was more likely than the family to think that cancer patients can recover from cancer (87.4% vs 75.4%, $P<0.001$). No significant differences were found between the three questions in Figure 1 and different age groups (<30, 31–50, 51–70 and >70 years) in the patient or the family groups.

Concerning factors that could help individuals accept the cancer diagnosis, nonsignificant differences were observed between the patient and the family groups. Three factors were chosen by both groups as most important: 1) religion, 2) relationship between doctor and patient, and 3) support from family and friends (Table 2). In terms of attitude after CDD, fear was most commonly selected by both patient and family groups, although it was chosen more by the family group (56.3% vs 70.4%, $P<0.001$), while acceptance was chosen more by the patient group (38% vs 15.2%, $P<0.001$).

Binary logistic regression analyses

This study involved binary logistic regression to explore factors that could contribute to the three questions in Figure 1. The study analyzed the following: participant group (either patient group or family group), gender, age, education level, having information about cancer, and employment status (Table 3).

For Question 1 as a response variable, having information about cancer and being employed were the only two categories favoring the response variable. While for Question 2 as a response variable, being a patient in the group was the only variable with a significant association. Finally, for Question 3 as a response variable, being a patient, having information about cancer, and being employed were found to significantly predict the response variable.

Discussion

Preference of cancer disclosure

The results of this study confirm patient preference for CDD and related information, as has been shown in previous studies in Saudi Arabia, and around the world.[5,7,10,12,13] We add to the literature one more study about the perception toward CDD of patients and their families. Despite the importance of this topic, it has only been investigated by a single recent study, from Zekri et al.[10] We found that cancer patients preferred to be informed about the cancer diagnosis more than their families (82.6% vs 75.3%, $P<0.05$). However, when both patient and family groups were asked about their preferences toward detailed information about cancer status (in terms of cancer stage, prognosis, and management), the

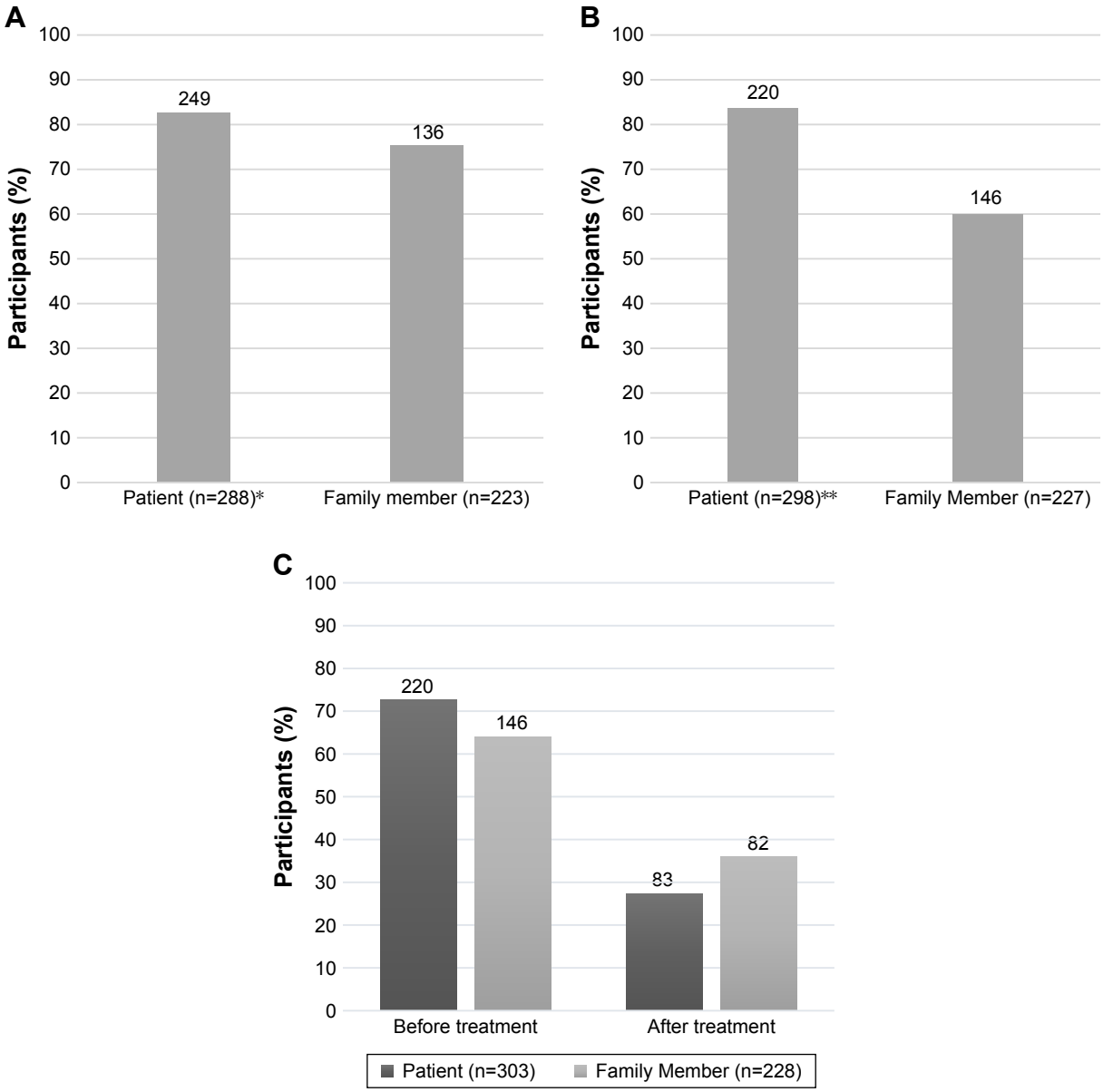

Figure 1 The percentage of participants who answered "yes" to the following questions: (**A**) Do you think a patient should be informed about cancer diagnosis? (**B**) Do you think a patient should be given all the details of his cancer status? (**C**) When do you think a patient should be informed about cancer? *$P<0.05$; **$P<0.001$.

gap between group preferences was found to be larger (83.6% vs 59.9%, $P<0.001$).

Similarly, recent results of a Saudi study[10] found that 52% of patients' family members, compared with 85% of patients ($P<0.001$), preferred disclosure of information regarding cancer (diagnosis, possible poor outcome, chemotherapy, failure of treatment, changes in condition and outcome, serious health updates, and lack of specific anticancer treatment options), while the gap between the preferences of both groups was found to be closer when asked about disclosure preference for cancer diagnosis only (patient: 87% vs family: 68%, $P<0.001$). This gap in preferences may have reflected how much knowledge about the cancer prognosis was provided to cancer patients and their family members in the cancer journey. Moreover, studies from Western and non-Western countries[14,15] found approximately 80% of family members and only 30%–60% of patients were aware when the cancer had become terminal.[16] In conclusion, this may indicate the tendency of family members to prefer disclosure of scarce cancer-related information to cancer patients.

Reasons for disclosure and nondisclosure

Part of the explanation of the family group preference of scarce information to the patient, in our study, can also be contributed to the reasons that they chose for nondisclosure. Among the reasons for nondisclosure, preventing a negative

Table 2 Differences in attitudes toward disclosure of cancer diagnosis

Factors that help patient in accepting cancer diagnosis	Patient n=304	Family member n=277	*P*-value
Support from family and friends	257 (85.1%)	209 (90.5%)	0.06
Relationship between the doctor and the patient	264 (87.4%)	206 (89.2%)	0.53
Relationship between the nursing staff and the patient	220 (72.8%)	166 (71.9%)	0.80
Religion	277 (91.7%)	211 (91.3%)	0.87
Quality of health care	230 (76.2%)	182 (78.8%)	0.47
Location of treatment	210 (69.5%)	167 (72.3%)	0.48
Knowing that the patient will be cured	219 (72.5%)	177 (76.6%)	0.28
Reasons for cancer disclosure	**Patient n=241**	**Family member n=170**	
To better organize remaining life	169 (70.1%)	121 (71.1%)	0.81
To help in treatment course	181 (75.1%)	132 (77.6%)	0.55
To improve family relationships	59 (24.4%)	55 (32.3%)	0.79
To avoid living under an illusion	100 (41.4%)	83 (48.8%)	0.14
To get several medical advices	58 (24%)	52 (30.5%)	0.14
Reasons for cancer nondisclosure	**Patient n=55**	**Family member n=48**	
To prevent a negative effect on the patient	37 (67.2%)	37 (77%)	0.59
To avoid change in daily life	9 (16.3%)	11 (22.9%)	0.56
To avoid pity from others	22 (40%)	22 (45.8%)	0.31
No treatment for cancer	3 (5.4%)	8 (16.6%)	0.10
What is the possibility to recover from cancer?			
<50%	37 (12.6%)	56 (24.6%)	0.00[a]
>50%	256 (87.4%)	172 (75.4%)	
Patient's reaction to disclosure of cancer			
Denial	12 (4%)	14 (6%)	0.27
Fear	169 (56.3%)	162 (70.4%)	0.00[a]
Anger	10 (3.3%)	10 (4.5%)	0.54
Confusion	35 (11.6%)	38 (16.5%)	0.10
Acceptance	114 (38%)	35 (15.2%)	0.00[a]
Sadness	72 (24%)	65 (28.2%)	0.26

Note: [a]$P<0.001$.

effect on the patient (77%) emerged as the most popular. This may reflect the intention of family members to protect cancer patients from psychological distress, which is thought to be the most important factor for preference of nondisclosure.[17,18] A recent study completed in Egypt, a country with a similar culture to Saudi Arabia,[19] found that family members who preferred a nondisclosure of cancer diagnosis to patients also responded that they would prefer not to know their own cancer diagnosis in the event that they developed cancer. This may reflect their own fear of psychological distress.

The three reasons for cancer disclosure in our study were as follows: helping patient's treatment, organizing their lives, and avoiding living under an illusion. These reasons were selected by both the patients and their family members more than any other reasons. In essence, these are among the main benefits of CDD to patients; taken collectively, they improve the patient's quality of life. A recent study indicated that patients who were informed about their cancer treatment were found to have better health competence, a greater sense of control over cancer, and improved symptom management.[20] On the contrary, noninformed patients were found to have higher levels of anxiety and irritability than informed patients.[21]

Important factors in acceptance of cancer disclosure

In response to questions concerning the factors that help patients and family members accept cancer conditions, religion (91%), relationship between doctor and patient (patient: 87.4% vs family: 89.2%), and support from family and friends (patient: 85.1% vs family: 90.5%) were the three factors chosen more than any others. Religion is a fundamental influence for the decision-making of Muslims. A recent study[22] found that 74.3% of Muslim patients with colorectal cancer responded that their entire approach to life was based on religious beliefs. In another study, 90% of medical patients reported that religious beliefs helped them

Table 3 Binary logistic regression analysis predicting disclosure of cancer

Variable	Do you think a patient should be informed about cancer diagnosis? (yes)		Do you think a patient should be given all the details of his cancer status? (yes)		When do you think a patient should be informed about cancer? (before treatment)	
	OR	95% CI	OR	95% CI	OR	95% CI
Group						
Family	1		1[a]		1[b]	
Patient	1.38	0.88–2.15	3.26	2.11–5.05	1.59	1.05–2.41
Gender						
Female	1		1		1	
Male	0.63	0.39–1.00	0.85	0.54–1.36	0.69	0.44–1.07
Age						
50 and older	1		1		1	
Younger than 50	1.42	0.85–2.38	1.46	0.88–2.42	1.26	0.78–2.01
Education						
Lower than high school	1		1		1	
Higher than high school	1.23	0.71–2.11	1.20	0.70–2.04	1.21	0.73–2.01
Cancer information						
Not having information about cancer	1[b]		1		1[a]	
Having information about cancer	1.80	1.15–2.84	1.48	0.95–2.29	1.93	1.27–2.94
Employment						
Not employed	1[b]		1		1[a]	
Employed	1.77	1.00–2.82	1.64	0.98–2.76	2.08	1.25–3.44

Notes: [a]$P<0.001$; [b]$P<0.05$.
Abbreviations: CI, confidence interval; OR, odds ratio.

to cope with their illness.[23] This religious background may have led 91% of our participants to select religion as a key factor for accepting a cancer diagnosis. However, further exploration of religion as a contributing factor in acknowledging cancer diagnosis is warranted.

The result that the relationship between doctor and patient is one of the most important factors in accepting a cancer diagnosis aligns with recent studies that have found an association between doctor–patient communication and cancer patient outcomes, especially satisfaction, psychological morbidity, and understanding.[24] In regard to the support of family and friends, the Middle Eastern cultural and religious values of participants encourage them to provide support to their relatives in need.[7]

Patient reaction to disclosure and cure rate

Concerning patient reaction to cancer disclosure, negative emotions (denial, fear, anger, and sadness) were expected by families to emerge, more than what patients expected themselves. This is particularly true for fear, as our study found statistical differences between the two groups (patients: 56.3% vs families: 70.4%, $P<0.001$). Indeed, many studies have found cancer to be the most feared disease.[25,26]

A recent study in Lebanon[11] found that both patient and family groups expected fear (33%) as the first reaction of the patient to cancer disclosure with nonsignificant differences. The study found fear to be the most difficult feeling a cancer patient may have to experience (63% of all participants).[11] On the other hand, acceptance, a positive emotion was expected by patients more than their families (38% vs 15.2%, $P<0.001$).

In addition to this, family members not only expected patients to show negative emotions but also they were more negative in terms of recovery rate (families: 75.4% vs patients: 87.4%, $P<0.001$). These findings may indicate that the family is more pessimistic than the patient group toward the cancer treatment, or that the patient group is more hopeful and optimistic than the family.

Study limitations

Our study had several limitations. First, we used convenient sampling. Using probability sampling method would have been a better method, especially if the patients and family members were matched based on time since cancer diagnosis, extent of cancer knowledge, or relation to patient. Second, the family members accompanying the patients might not have been representative of all family members. Finally, participants were recruited from only one hospital.

Clinical implications

This study indicates the preference of families toward non-disclosure attitudes for cancer diagnosis.[5,10,12] It also shows

the tendency of families to disclose only limited cancer information as the disease progresses. Therefore, physicians need to be vigilant in discerning how much information cancer patients actually possess throughout the treatment process.

To ease the nondisclosure attitude of family members of cancer patients in non-Western cultures, we suggest addressing any fears that families may have on causing psychological distress on the patients. As we mentioned earlier, this reason is thought to be the most important factor for nondisclosure,[18] and was the most popular selection among other reasons in our sample. This can be facilitated by utilizing physician–patient communication protocols described in the literature – one of the most renowned is the SPIKES protocol[27] – as well as applying suggested approaches for culturally competent communication.[28,29] Finally, we recommend educating families about the benefits of well-informed patients, which include, among other things, better health competence, greater sense of control over cancer, and improved symptom management.[20]

Conclusion

This study provides insight into the attitude of cancer patients and their families toward cancer diagnosis in a sample of participants from Saudi Arabia. We found that most patients preferred full disclosure of all details of their cancer treatment, while families were more inclined to providing scarce information. Fear and pessimistic expectations toward cancer disclosure and its management characterized the experience of family members, but was less common among patients. Ultimately, we proposed that the physician–patient relationship and family support play a crucial role in facilitating CDD and its related information. The findings of this study, concerning patient and family preferences and attitudes, can be utilized to provide more effective cancer treatment.

Ethical approval

The study took place over the period between June 2016 and February 2017. The study and verbal consent process was approved by the Institutional Review Board of King Abdullah Medical City (number 16–259).

Acknowledgment

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Disclosure

The authors report no conflicts of interest in this work.

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