What Do Patients with Cerebral Aneurysms Know About Their Condition?

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OBJECTIVE: During diagnosis and treatment, patients with cerebral aneurysms receive complex medical information. To study what patients know about their condition, we compared patients' knowledge about their aneurysm-related medical history with information in the medical record.

METHODS: Neurosurgery clinic outpatients with cerebral aneurysms were interviewed about their history of subarachnoid hemorrhage, number of aneurysms, aneurysm treatments, and treatment outcomes. Corresponding data were abstracted from the medical record by study personnel. We used κ scores to assess the agreement between patient responses and the medical record.

RESULTS: The 178 study patients were predominantly women (71%), with a mean age of 54.4 years. The medical record showed that 56% of patients currently harbored an unsecured aneurysm, 53% had experienced a subarachnoid hemorrhage, 29% had multiple aneurysms, and 68% had undergone previous surgical or endovascular aneurysm treatment. Patient responses showed that, of the 100 patients with unsecured aneurysms, 33% were not aware that they harbored an unsecured aneurysm. Ninety percent of all patients knew whether they had experienced a subarachnoid hemorrhage (κ = 0.81, near perfect agreement), 78% knew how many aneurysms they harbored (κ = 0.57, moderate agreement), and 92% understood whether they had undergone previous aneurysm treatment (κ = 0.82, near perfect agreement).

CONCLUSION: Most patients with cerebral aneurysms had an accurate understanding of many aspects of their aneurysm-related medical history. Of concern, patients were most often incorrect about the presence of an unsecured aneurysm, the issue most relevant to treatment decision-making and to their future risk of subarachnoid hemorrhage, stroke, and premature death.

KEY WORDS: Cerebral aneurysms, Decision-making, Embolization, Outcomes, Surgery, Treatment

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Patients' knowledge of their medical condition can improve the outcome of care (7, 8). However, patients often have difficulty understanding and recalling details of their condition. Patients' understanding of prevalent conditions such as hypertension, heart disease, or cancer may be improved by public health initiatives (e.g., Healthy People 2010 [3]) designed to raise the public awareness of disease symptoms, risk factors, and treatments. Less common medical conditions are generally not the focus of public educational programs, and patients usually obtain knowledge about their disease from health care providers after diagnosis. Cerebral aneurysms are a relatively uncommon condition, present in approximately 2% of the population (17), and most affected individuals are unaware that they harbor an aneurysm. Aneurysmal subarachnoid hemorrhage (SAH) is even more rare, occurring in only 0.04% of the population annually (17). In addition, cerebral aneurysms represent a complex clinical condition involving a vital organ with several sophisticated treatment options. The relative unfamiliarity and complexity of cerebral aneurysms may make it challenging for patients to recall certain details about their condition such as number of aneurysms, history of SAH, treatments, and treatment results.

To obtain a better understanding of what patients with cerebral aneurysms understand

about their condition, we studied patients in a vascular neurosurgery clinic. As part of a larger study of quality of life in patients with cerebral aneurysms, we measured patients' knowledge about the current state of their aneurysms and about their aneurysm-related medical history. We then compared patients' responses with data extracted from the medical record.

METHODS

Data Collection

We studied patients at University of Pittsburgh Medical Center neurosurgery clinics recruited between June 2001 and February 2004. All patients with one or more cerebral aneurysms and sufficient English language and cognitive skills to complete the interview were eligible. After obtaining informed consent, the patients underwent a structured interview administered by a trained research assistant to obtain data on demographics, education, habits, comorbid diseases, and details of aneurysm history. Additional aneurysm data were abstracted from paper and electronic medical records using standardized data collection forms and practices. Patients completed the Mini Mental State Examination (MMSE); scores on the MMSE can range from 0 to 30, and scores less than 24 were considered indicative of cognitive impairment (6). Patients also completed the Hospital Anxiety and Depression scale, generating anxiety and depression scores ranging from 0 to 21 (20). Hospital Anxiety and Depression subscale scores of 11 or greater are indicative of anxiety or depression. The study protocol was approved by the institutional review boards of Yale University and the University of Pittsburgh. Patients received $25.00 after completing the interview.

Statistical Analysis

Categorical variables were tabulated, and means and standard deviations were calculated for continuous variables. We compared the characteristics of the patients with complete aneurysm data to study participants with missing aneurysm data using Fisher's exact test for categorical variables and the Mann-Whitney *U* test for continuous variables. Patients' knowledge of their aneurysms and treatments were compared with data abstracted from the medical record by using unweighted κ scores. κ scores measure how closely two assessments of the same item agree beyond that expected from chance alone and quantify agreement as follows: 0 to 0.20, slight agreement; 0.21 to 0.40, fair agreement; 0.41 to 0.60, moderate agreement; 0.61 to 0.80, substantial agreement; and 0.81 to 1.00, almost perfect agreement (10). We used stepwise logistic regression to analyze which factors (age, sex, race, high school education, cognitive functioning, depression, anxiety, hypertension, cigarette smoking, SAH, number of aneurysms, presence of an unsecured aneurysm, previous aneurysm treatment) were associated with better patient understanding of their aneurysm condition. We also ran separate stepwise logistic regression analyses to explore the relationships between what patients believed about their aneurysms (e.g., SAH, presence of an unsecured aneurysm), mental health (e.g., depression, anxiety), and modifiable risk factors (e.g., hypertension and cigarette smoking) for aneurysm formation and rupture, adjusting for cognitive functioning. For logistic regression modeling, simple logistic regression was used to select predictor variables where $P < 0.200$ was used for candidate inclusion in the multivariate stepwise logistic model. In the final logistic models, $P < 0.05$ was considered significant, and $P \geq 0.05$, but < 0.100, was considered a statistical trend.

RESULTS

Study Population

During the course of the study, 275 patients with cerebral aneurysms were seen in the neurosurgery clinics, 217 (79%) consented to participate in the study, and 178 (65%) patients provided details of their aneurysm history and comprised our analysis sample. Incomplete data collection was caused by patient time constraints and scheduling conflicts rendering research staff unavailable to perform interviews. In comparing the study sample of 178 patients with the 39 patients with incomplete aneurysm data collection, the study sample had a higher proportion of patients with an unsecured aneurysm (56 versus 36%; $P = 0.022$). There were no significant differences between the study sample and the excluded patients in age, sex, race, education, cognitive functioning, depression, anxiety, hypertension, cigarette smoking, history of SAH, number of aneurysms, or previous aneurysm treatments (for all, $P \geq 0.200$). The mean $\pm$ standard deviation patient age was 54.4 $\pm$ 13.0 years, 71% of the patients were women, 53% of patients had experienced a previous SAH, 29% had multiple aneurysms, 68% had undergone previous surgical or endovascular aneurysm treatment, and 56% harbored an unsecured aneurysm (*Table 1*).

Comparison of Patient Responses with the Medical Record

Unsecured Aneurysms

Of the 100 study patients with an unsecured aneurysm documented in the medical record, 34% had experienced a SAH, 45% had undergone previous aneurysm treatment, 18% had posterior circulation aneurysms, and 27% had aneurysms measuring 10 mm or greater in diameter. Thirty-three percent of these 100 patients were unaware that they had an unsecured aneurysm. Conversely, only 11 (14%) of the 78 patients whose aneurysms had been obliterated mistakenly thought that they had an unsecured aneurysm. Considering the responses of all 178 patients, 45 (25%) were wrong about whether they had an unsecured aneurysm ($\kappa = 0.51$, moderate agreement) (*Table 2*). The stepwise multivariate logistic regression model failed to show any relationship between patient knowledge about the presence of an unsecured aneurysm and

TABLE 1. Study population

Total	n = 178
Age	
Mean ± standard deviation	54.4 ± 13.0
Range	25–90
Sex	
Female	71%
Race	
Non-Hispanic white	93%
Education	
High school or technical school graduate	90%
Mini mental state examination	
Score 0–23 (cognitive impairment)	35%
Hospital anxiety and depression scale	
Depression score > 11	9%
Anxiety score > 11	17%
Hypertension	
Diagnosis (under treatment)	63% (56%)
Cigarette smoking	
Current	27%
Prior history	75%
Previous subarachnoid hemorrhage	53%
Number of aneurysms	
1	71%
2	17%
3	8%
4	2%
5	0.6%
7	0.6%
Patients with unsecured aneurysm(s)	56%
Previous aneurysm treatment(s)	
Surgery	49%
Endovascular embolization	16%
Both	3%
None	32%

age, sex, race, education, cognitive functioning, depression, anxiety, hypertension, cigarette smoking, previous SAH, previous aneurysm treatment, or type of previous treatment (surgery versus endovascular embolization) (*Table 3*).

Subarachnoid Hemorrhage

There was 90% agreement between patients and the medical record about a history of SAH (κ = 0.81, almost perfect agreement) (*Table 2*). The regression model showed significantly less accurate knowledge about their history of SAH in patients with a history of SAH (odds ratio [OR] = 0.30; 95% confidence interval [CI] 0.09, 0.96; P = 0.043) and a trend toward better understanding of that history in patients with at least a high school education (OR = 3.6; 95% CI 0.99, 13.1; P = 0.052; logistic model P = 0.020) (*Table 3*). There was no relationship between patient knowledge about their history of SAH and age, sex, race, cognitive functioning, depression, anxiety, hypertension, cigarette smoking, previous aneurysm treatment, or type of previous treatment.

Number of Aneurysms

Seventy-eight percent of patients' responses were in agreement with the medical record about their number of aneurysms (κ = 0.57, moderate agreement) (*Table 2*). The regression model showed no relationship between patient knowledge about how many aneurysms they had and age, sex, race, education, cognitive functioning, depression, anxiety, hypertension, cigarette smoking, previous SAH, previous aneurysm treatment, or type of previous treatment (*Table 3*).

Previous Aneurysm Treatment

Ninety-two percent of patients agreed with the medical record about whether they had undergone aneurysm surgery or endovascular embolization in the past (κ = 0.82, almost perfect agreement) (*Table 2*). The regression model showed more accurate knowledge about history of aneurysm treatment in patients who had undergone any type of aneurysm treatment in the past than among those with no previous aneurysm treatment (OR = 3.5; 95% CI 1.1, 11.5; P = 0.041) and a trend toward worse knowledge in patients with impaired cognitive functioning measured with the MMSE (OR = 0.15; 95% CI 0.02, 1.2; P = 0.075; logistic model P = 0.006) (*Table 3*). There was no relationship between patient knowledge about their history of SAH and age, sex, race, education, depression, anxiety, hypertension, cigarette smoking, previous SAH, or type of previous aneurysm treatment.

Aneurysm Risk Factors

Hypertension

One hundred and twelve (63%) patients had hypertension, and, of those, 97 (87%) reported receiving treatment. In multivariate analysis, hypertensive patients who reported a history of SAH or an unsecured aneurysm were no more likely to be on antihypertensive medication than patients who had never experienced a SAH or who had undergone successful obliteration of all aneurysms (*Table 3*).

Cigarette Smoking

A total of 132 (75%) patients had a history of cigarette smoking. Forty-seven (27%) were current smokers and 85 (48%) had quit smoking. In multivariate analysis, cigarette smokers who reported a history of SAH or an unsecured aneurysm were no more likely to quit smoking than patients who had never experienced SAH or who had undergone successful obliteration of all aneurysms (*Table 3*).

DISCUSSION

Cerebral aneurysms have complicated and variable natural histories, prognoses, treatment options, and treatment out-

TABLE 2. Agreement between patients and the medical record[a]

Information	Actual agreement (%)	Expected agreement (%)	κ^b	*P* value
Previous SAH	90	50	0.81	<0.001
Number of aneurysms	78	49	0.57	<0.001
Current unsecured aneurysms	75	49	0.51	<0.001
Previous aneurysm treatments	92	57	0.82	<0.001

[a] SAH, subarachnoid hemorrhage.
[b] Interpretation of κ scores: 0.0–0.20, slight agreement; 0.21–0.40, fair agreement; 0.41–0.60, moderate agreement; 0.61–0.80, substantial agreement; and 0.81–1.00, almost perfect agreement.

comes. Patients receive information about their aneurysms from healthcare providers, and some patients have difficulty recalling details of their aneurysm history. In our study population, landmark events such as SAH or surgical or endovascular treatment are recalled with greater than 90% accuracy. Less prominent factors, such as the number of aneurysms, are recalled at a slightly lower rate (78%). Surprisingly, patients were least knowledgeable about whether they still harbored an unsecured aneurysm. Among the 100 patients that harbored an unsecured aneurysm, one-third were not aware of its existence. In other words, patients were least likely to know the aspect of their disease that was arguably most relevant to their need for treatment and to their future risk for SAH, stroke, and premature death: the presence of an unsecured cerebral aneurysm.

Deficiencies in patient understanding may be caused by inadequate communication between healthcare providers and patients, confusing medical terminology, poor patient recall or information overload, emotional stress, failure of patients to incorporate new information, and even patient denial. Several methods have been used to improve the flow of information between the healthcare system and patients. Experimental educational interventions designed to improve physician communication skills have met with mixed results (2, 5, 12, 18). Government agencies such as the Centers for Disease Control and Prevention maintain internet sites emphasizing public education (3). Many professional societies publish educational print or electronic materials to inform patients about specific conditions. For example, the Congress of Neurological Surgeons has created illustrated text-based materials about a variety of neurosurgical conditions, tests, and procedures (e.g., low back pain, angiography, brain tumor surgery) that can be read or downloaded from its web site (4). In the research realm, computerized videodisc programs have been used to successfully educate patients with back pain (16), benign prostatic hypertrophy (1, 15), menopausal symptoms (14), and ischemic heart disease (13). However, effective, customized programs are expensive to create and thus may not be a practicable general solution.

Patients often have difficulty comprehending medical terminology. When surgery or embolization fails to completely obliterate an aneurysm, physicians may describe the treatment results using terminology (e.g., "dog-ear," "incomplete obliteration," "remnant," "coil compaction," and "contrast percolation") that patients may misconstrue to mean that the aneurysm has been obliterated. Patients may fail to correctly recall what they were told by the physician. The stress of recently learning about a potentially life-threatening condition may impair information transfer and recall. The status of an aneurysm can change over time, and patients may fail to update their understanding of their aneurysm with available information. For example, some aneurysms may thrombose spontaneously, "disappearing" from later imaging studies. Conversely, aneurysms that appear to be obliterated on initial postembolization angiograms may subsequently recanalize or undergo coil compaction, "reappearing" on follow-up angiograms. Intraoperative angiograms that seem to show successful aneurysm clipping may be technically inadequate to demonstrate incomplete obliteration. Even when patients are told that the current imaging study demonstrates a change in their aneurysm status, they may preferentially recall a more favorable earlier report.

We tried to identify factors associated with patient knowledge of their aneurysm condition, but we found inconsistent associations with education, cognitive functioning, previous aneurysm rupture, and previous aneurysm treatment. Patients with a history of SAH were less likely to correctly report whether they had experienced SAH, and patients with cognitive impairment documented by the MMSE were less likely to correctly report whether they had previously undergone aneurysm treatment. Although one would expect deleterious effects on recall associated with SAH and cognitive impairment, it is unclear why these adverse effects were confined to specific historical items. Patients with at least a high school education more often correctly reported having had SAH, and patients who underwent previous aneurysm treatments were more likely to correctly recall those treatments. The isolated effect of previous treatment on correct recall of whether a patient had undergone previous treatment is understandable. Undergoing aneurysm treatment is a memorable event. Of note, among patients with previous aneurysm treatments, we were unable to show any differences in recall when comparing patients who had undergone surgery versus endovascular embolization. We acknowledge that patients who have experienced SAH are quite different from those who have never had a hemorrhage; the former have survived a catastrophic, life-threatening event and most live with the sequelae for the rest of their lives. However, with the exception of greater difficulty remembering their SAH, our current study did not find differences between SAH and non-SAH patients in their

TABLE 3. Multivariate logistic regression model results[a]

Dependent variable	Independent predictor variables			Final model	
	Variable	Odds ratio (95% CI)	*P* value	Pseudo R^2	*P* value
Accurate patient knowledge of the presence or absence of an unsecured aneurysm (n = 178)	—	—	—	*	*
Accurate patient knowledge of their history of SAH (n = 176)	SAH	0.30 (0.09, 0.96)	0.043	0.07	0.020
	High school education	3.6 (0.99, 13.1)	0.052	—	—
Accurate patient knowledge of their number of aneurysms (n = 161)	—	—	—	*	*
Accurate patient knowledge of whether they had previous aneurysm treatments (n = 151)	Previous treatment	3.5 (1.1, 11.5)	0.041	0.11	0.006
	MMSE cognitive impairment	0.15 (0.02, 1.2)	0.075	—	—
Taking antihypertensive medications (hypertensive patients only; n = 112)	—	—	—	*	*
Successfully quit cigarette smoking (smokers only; n = 132)	—	—	—	*	*

[a] CI, confidence interval; SAH, subarachnoid hemorrhage; MMSE, mini mental state examination. Asterisk indicates that pseudo R^2 and *P* values are absent because there were no statistically significant predictors of the dependent variable in the model.

aneurysm knowledge or modifications of aneurysm risk factors.

Patients are in a position to obtain proper care if they 1) are aware of their medical condition, 2) understand their treatment options (including modification of risk factors), 3) have access to treatment, and 4) are motivated to complete the care plan. The flawed understanding of a sizable minority of our patients could have adverse health consequences if the lack of knowledge interferes with obtaining appropriate care. Studies involving the management of common diseases in primary care patients suggest that cerebral aneurysm outcomes might be improved by enhancing patient understanding of their condition (7, 8). Although patient understanding seems to be beneficial in the primary care setting, we do not know whether patient knowledge improves outcomes in a surgical subspecialty such as neurosurgery. During office visits, surgeons interact differently with their patients than do primary care physicians (11, 19), implying a different structure to the physician-patient relationship. In such settings, patient knowledge may not be as important to adherence or outcomes.

Our sample population was derived from patients under care at a single university hospital, and thus the results may not be generalizable to other institutions or other types of healthcare delivery systems such as private practices or heath maintenance organizations. Not all eligible patients enrolled in our study, and some who did enroll failed to complete all surveys. Of note, there was only one minor difference between the study sample and the unanalyzable patients. We accepted the electronic and paper medical record as the gold standard of comparison for our analyses; however, errors and inconsistencies can creep into the medical record, and some discrepancies between patients and the medical record may be caused by legitimate patient disagreements with medical record errors. It is also possible that healthcare providers may have conveyed inaccurate information to patients. We did not collect data on the date of aneurysm diagnosis or on who referred the patients for neurosurgical consultation, and thus we were unable to look at possible relationships between patient understanding and interactions with other healthcare providers or duration of aneurysm awareness.

We postulated that patients who had survived an aneurysmal SAH or who were aware that they harbored an unsecured aneurysm would be more attuned to their risk of subsequent problems and thus might be more likely to stop smoking or undergo treatment for their hypertension. Our data do not show better adherence with antihypertensive medication or a greater likelihood of smoking cessation in patients with unsecured aneurysms or in those who had experienced SAH. There are several possible explanations for this finding: 1) ignorance, patients were not aware of a link between the risk factors and

adverse outcomes; 2) access issues, patients were unable to obtain care because of logistical or financial barriers; and 3) insufficient motivation, patients were unwilling to act to reduce their risks. Patients may not have been aware of the relationship between smoking and hypertension on aneurysm formation and rupture. Such a knowledge deficit would represent a failure of the healthcare system to effectively educate patients with aneurysms about their disease. Substantial communication deficits have been shown to exist between neurosurgeons and their patients with aneurysms when discussing treatment options and risks (9). Similar problems may exist when discussing (or failing to discuss) risk factors for aneurysm formation and rupture. Access to smoking cessation programs, to healthcare providers to manage hypertension, and to antihypertensive medications may have been limited by transportation, economic, or insurance issues. Alternatively, patients may have understood the importance of hypertension treatment and smoking cessation, but they may have been unwilling or unable to modify their behavior. Perhaps future work collecting data on knowledge of risk factors, access to interventions (e.g., medications, counseling), and motivation and attempts to alter risk factors will pinpoint the problem area(s) and allow the design of an effective intervention. In the meantime, healthcare providers should consider making greater efforts to communicate effectively with patients who have experienced SAH, have less than a high school education, or who have cognitive impairment.

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COMMENTS

This study documents a surprising level of misunderstanding by aneurysm patients treated at the University of Pittsburgh Medial Center. Only 92% of the patients knew whether they had been treated for an intracranial aneurysm, and 33% of the patients with an untreated aneurysm were not aware that they harbored such a lesion. Another 14% of the patients without any untreated aneurysms thought that they still had an aneurysm. Whether this confusion related to poor communication between health care providers and patients or patient cognitive problems is not clear from the discussion. Perhaps more involvement of family and close friends in the health care of patients with cognitive limitations would improve understanding and treatment compliance.

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In this study of 178 aneurysm patients, the authors compared patients' knowledge about their aneurysm history with information in their medical records. Landmark events such as aneurysm rupture and treatment were recalled accurately, but the issue most relevant to future risk of rupture and treatment decisions, namely, the presence of an unsecured aneurysm, was not recalled accurately by 33% of the 100 patients with such aneurysms. Another striking finding was that patients who survived an aneurysm rupture or were aware of an unsecured aneurysm were not more likely to address risk factors for aneurysms (quit smoking and control blood pressure) than patients with unruptured or completely treated aneurysms. The authors discuss the reasons for deficient patient understanding, including inadequate communication with doctors, confusing medical terminology, information overload, stress, and denial. The authors also discuss the reasons for patient inaction in controlling risk factors, including ignorance, poor access to care, and lack of personal

motivation. This report indicates that, despite our best efforts, a sizable majority of our patients do not hear our message. This report challenges us to find better ways to transmit vital information to patients and make certain that it is understood.

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King et al., as part of a larger study that describes quality of life among patients with cerebral aneurysms, measured patient knowledge about their condition. Information from a variety of sources was collected on 178 patients. Half these patients had a ruptured aneurysm. Most knew whether they had a subarachnoid hemorrhage (90%), how many aneurysms they had (78%), or whether they had received treatment (92%). However, among the patients in whom knowledge about their condition is most important (i.e., those with an unsecured aneurysm), only one-third had an accurate understanding of their disease. Surprisingly, education status, cognitive function, depression, or anxiety had little impact on patient knowledge.

There are several limitations to this study and potential biases in data collection. However, the authors acknowledge this and thus provide a worthwhile addition to our knowledge of what patients know about their disease. This is important because several lines of evidence, particularly in primary care, demonstrate that patient knowledge can improve care and outcome. And, when there is a poor outcome, this may reduce the likelihood of legal action. How patients interact with primary care physicians and specialists such as neurosurgeons is different, and it is not known whether patient knowledge can impact outcome among patients with cerebral aneurysms. King et al.'s study is a welcome preliminary step into understanding how patient education may influence outcome. At the same time, it emphasizes the importance of clear physician-to-patient communication.

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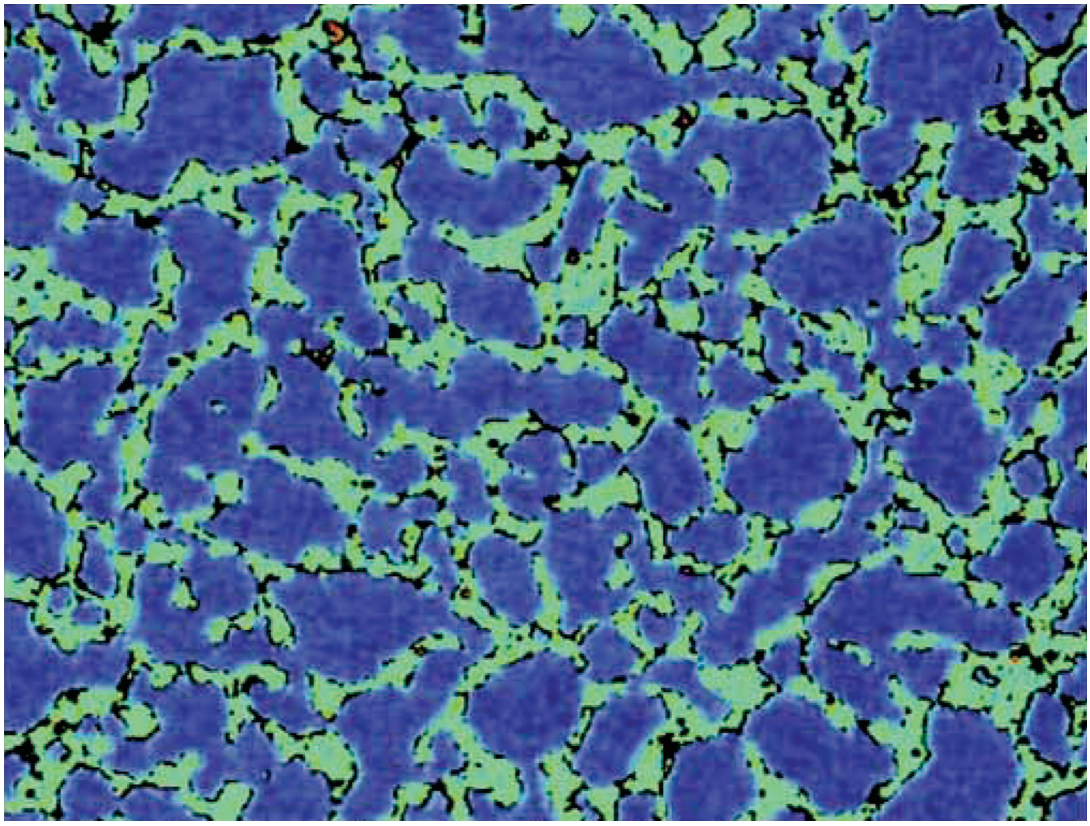

Biodetection utilizing nanomedical materials. Optical profilometer plot of Streptococcus mutans, *captured by immobilized antibodies. The bacteria have been stained to enhance contrast. (Ho D, Fung AO, Montemagno CD. Engineering novel diagnostic modalities and implantable cytomimetic nanomaterials for next-generation medicine.* ***Biol Blood Marrow Transplant****. 2006 Jan;12(1 Suppl 1):92–9.)*