The importance of the patient's voice in nuclear cardiology

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In 2001, the Institute of Medicine published “Crossing the Quality Chasm”; a report that gave us six aims on how to improve the quality of health care in America. One of those aims was for care to be patient-centered, which they defined as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.”¹ (Figure 1) In the intervening two decades, patients have contributed more to the delivery of health care although not always in ways that put them in the center of the process.

In this issue of the Journal, Li et al investigate the factors contributing to patient centeredness of myocardial perfusion imaging (MPI) through a representative national survey of patients, physicians, and imaging center staff, in roughly equal numbers. The participants rated the importance of a variety of factors potentially affecting the patient experience of MPI. The authors compared the ratings to determine where the three groups of participants agreed or disagreed.

One of the most interesting findings was the responses related to direct patient access to test results.

Median rating on this factor from patients was 8 (on a scale from 0 to 10), while physicians rated it as 6. That rating does not clearly indicate that physicians think that the patient access to test results is unimportant, but it does show a difference in priority between the groups. The difference speaks to a mismatch between what some clinicians think is being patient-centered and what actually puts patients at the center of the care they receive.

Patient access to medical records has evolved substantially since the time of “Crossing the Quality Chasm”. The Health Insurance Portability and Accountability Act of 1996 or HIPAA, while often maligned as an example of government intrusion into healthcare, did have some good intentions. One of the key provisions is that individuals have the right to access their own health information.² Later, the Health Information Technology for Economic and Clinical Health Act would bring us the Meaningful Use program, now part of the Medicare Access and CHIP Reauthorization Act or MACRA.^{3,4} These programs sought to expand patient access to their health information through reimbursement incentives.

These government interventions may be driven, in part, by physician reluctance to allow open access of health records to patients. In a recently published survey of resident and attending physicians, 27% were concerned that patients’ open access to notes would increase the risk of lawsuits and 46% reported that it would change their documentation habits.⁵ In a qualitative study of primary care physicians, a number of concerns about open access to health information were raised, including generating unreimbursed workload and patient confusion.⁶ In a healthcare environment where burnout rates remain over 40%, adding to physician workload is an understandable concern.⁷ The underlying issue is not with increased patient autonomy, however, it is a healthcare system that overworks physicians and staff, causing injury to those trying to do their best to heal

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Figure 1. Domains of quality in healthcare.

their patients. Studies have shown that providing health information to patients without adequate explanation or context may frustrate patients or induce unwarranted anxiety.⁸ This concern needs to be balanced against the risk of physicians imposing a paternalistic interpretation of what is important for the patient to know.

Providing access for patients to their own health records may also improve the quality and usability of the records. At the 2019 American Society of Nuclear Cardiology (ASNC) meeting, Dr. Krishna Patel presented results from her ASNC sponsored grant on developing a patient-centered MPI report. Patients provided a number of suggestions on how to make MPI reports easier to understand including visual aids, personalized risk assessment, and treatment recommendations. The result was a MPI report that patients were more willing to read, better able to understand, and enhanced understanding of their cardiovascular risk.

Data privacy and security are additional concerns that need to be addressed. Hardly a month goes by without news of some corporation or industry that has failed to secure private financial or health information. In an interesting twist on the question of privacy, a recently conducted pilot program described a process for capturing patient preferences that would allow them to impose restrictions on their health information. In this approach, clinicians could be blocked from reviewing certain sensitive data areas including mental and reproductive health, HIV status, and substance abuse unless they could justify the need to see such information.⁹

Figure 2. MyHealtheVet web portal for patients.

As a model for how to expand patient access to health information, the Veterans Health Administration (VA) has been working for several years on the MyHealtheVet program which permits Veterans to refill prescriptions, track appointments, send secure messages, and access their health records. (Figure 2) Within the health records system, Veterans can build their own personalized health record and then customize, download, and print reports to share with non-VA clinicians. Veterans report that having full access to their records makes them feel more empowered, has enhanced understanding of their health, and their improved self-care.¹⁰ Veterans and clinicians alike have benefitted from being able to share records and voiced a desire for further opportunities to share health information.¹¹ The secure messaging system is a popular feature with 97% patient satisfaction.¹²

Li et al also asked several questions that may inform delivery choices, such as what patients think about having multiple pharmaceutical vasodilator agent options and the availability of the latest technology. Survey responses can inform our ongoing discussion about how to conduct a patient-specific MPI.¹³ The degree to which this concept is embraced could lead to many different imaging center models.¹⁴ Most of these choices are being made by physicians, and as experts in the field that is reasonable. When the imaging protocol options are in equipoise, however, could we not also ask the patient what they would want? The survey participants expressed that the time they spent in the imaging center was relatively important: How would patients feel about spending more time being imaged if it meant they could receive a lower dose of radiotracer? Would busy patients be interested in receiving a higher dose in order to be done with the test more quickly? What ethical issues arise in letting patients contribute to such decision making?

Health care systems around the world have a lot of room for improving the quality of care they deliver and patient centeredness is arguably the domain about which we know the least. Research, such as that done by Li et al, helps inform the discussion about making MPI a more patient-centered process. Looking forward, imagers and non-imagers alike need to be cognizant of the changes that are occurring in healthcare systems because our future success will likely be tied to how well we hear what our patients are trying to tell us.

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