COMMENTARY

Shared Decision Making, Vaccine Guidelines, and Public Health Authority: Reading Between the Lines

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When the president's commission first voted to endorse shared decision-making in 1981, they were not envisioning it being used to implement vaccination guidelines like those the Advisory Committee on Immunization Practices and the Centers for Disease Control and Prevention now offer.

Fast forward 40 years. Now, in their article entitled "Shared Decision-Making and Government Prevention Guidelines: Evolution, Implications, and Impediments" Lawrence and Schwartz should prompt us to wonder how it is that we got to this point. The emergence of what they call shared clinical decision-making (SCDM) as a recommendation category, particularly in vaccine guidelines "aim to acknowledge limited available data or inconclusive findings regarding key considerations such as long-term effectiveness, risk benefit ratio, or safety." Fair enough. Almost obvious.

However, stepping back a little, the recent trend of recommending SCDM implies a subtext exists to the emergence of that possibility within guidelines — a subtext that can be cyphered if not entirely decoded. That cyphering led me to wonder again about shared decision-making, the ethics of medicine, and how each fits into the authority and ethics of public health.

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In my cyphering, I noted that SCDM was not always plausible as a recommendation category; it only became plausible, recently. We should at least wonder how that came to be. What in the public imagination or the evolution of public health ethics, or the grading of evidence led us to this point? Perhaps vaccine guidelines need a short course in the history and sociology of science.

The shared decision-making bandwagon has now swelled so greatly, that the fact that some guidelines do not recommend SCDM may feel the oddest. At least for a generation of primary care doctors attentive to their information-hungry consumer-patient, even the most efficacious vaccine may entail a detailed conversation about risks and benefits — a kind of odd Portlandia of primary care, reflective of our moment.

Either way, my cyphering also prompted a wondering about how the implicit norms guidelines espouse about what SCDM is and is not — a concept that has been debated for decades that retains a certain resilient resonance and a disturbing slipperiness.[1] Most physicians think they do shared decision making, most patients aren't quite sure.[2] Most researchers, when they observe patients see little evidence of it.[3] And so for vaccine guidelines, absent a more transparent articulation of their lens, we as guideline readers are left to wonder whose version of shared decision making they deem desirable.

Using SCDM as a public health recommendation — as good and right as that may be at our particular moment in history, ought also to remind us of a crucial though somewhat unfashionable normative distinction — that the ends of public health and those of clinical medicine, though overlapping in the sphere of population health, diverge.[4] Public health takes group harm as its referent, seeking the good of the

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many, even at times at the expense of the liberty of a few. Clinical medicine begins more micro — striving for individual good, and occasionally zooming out to ensure its primary pursuit is not at cross-purposes with broader justice concerns. And the means each uses to pursue those ends may also diverge.

Such reflections and distinctions might then start making their way into how we think about the authority and ethics of public health. What then to make of the now routine recommendation of SCDM for vaccines like HPV or the pneumococcal vaccine in certain populations? The thoughts that came to mind for me bifurcate — at times toward the salubrious and at others toward the haunting.

Salubrious because, given the public confusion and outcry associated with vaccine hesitancy, conspiracy theories, and a strident faux-libertarian fad in our public life, who wouldn't want public health policymakers to wield the pen carefully. We should only make a strong recommendation when there is both strong evidence or imminent public health need. That guideline panels would exercise modesty in a middle way seems fitting, right, even good. When the evidence is unclear, don't overreach.

But skulking in the background of these seemingly flexible and accommodating maneuvers rests a different sort of worry, one that at least for me haunts. If policymaking bodies for guidelines get too comfortable offering soft recommendations, perhaps under pressure from advocacy groups, perhaps less confident in their role and worried about their legitimacy, or perhaps too attentive to growing public discontent with assertive centralized authority in the wake of a pandemic, then, down the road, even when it may be needed, that tendency to soften may metastasize to the point where governing bodies shrink from or altogether shirk their responsibility — to assert the right sort of public health authority when it is needed. An unused muscle soon becomes an atrophied one.

And with this atrophy grows a different sort risk germane to the middle way of SCDM — a risk of outsourcing. If we ask SCDM to bear all the burden, we ask it to do too much. Shared decision making should help patients and doctors navigate uncertainty, but it should not be a scapegoat for inexact science. Doctors like the support and certainty that guidelines recommend. And in the realm of vaccination discussions, these should be the easier part of a general medical exam, with built-in defaults — "unless you say otherwise, we'll go ahead and give X, Y, and Z."

Making SCDM do more work than it should not only adds more conversation burden to otherwise overwhelmed primary care providers, but would tacitly shift the blame when (not if) vaccination rates decline, putting doctors on the hot seat for prevention metrics. Dumping all the uncertainties about vaccine risks and benefits onto primary care doctors' for point-of-care adjudication seems both wimpy and unfair. And doing so could quickly become an unfunded public health mandate that would, over time, only weaken public health authority. It would amount to asking primary care doctors to routinely recite the vagaries they already have to navigate in, say, prostate cancer screening discussions, but now all day long with every demographic stratum. Spending one's whole day saying "the evidence is unclear, it may help, it may not; it depends in part on whether you are a risk taker, or a

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proactive type" — over and over again, doth not a fulfilling career make.

Instead of asking SCDM do all that work, we should insist on better evidence so that we can make stronger recommendations, ones that give reliable practice defaults, not ones that just acknowledge the uncertainty, throw up our hands, punt to doctors, and then walk away.

That SCDM emerged as a routine category within public health prevention recommendations mirrors important trends that have swept across medicine and our broader society. Those trends toward empowerment, transparency, and less paternalism have done a lot of good. But even as that trend continues, let's hope that more participation and empowerment do not devolve into abrogation of responsibility, outsourcing the hard work or becoming so comfortable with inconclusive evidence that we stop seeking a solid basis for strong public health recommendations when they are needed the most.

We've learned a lot in the last year and a half. There are and will continue to be times when public health authority will need to be exercised, even amidst evidentiary uncertainty and even if unpopular. That exercise is right and good. Doing so is a moral and prudential necessity.

Note

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References

1. J.C. Lawrence and J.L. Schwartz, "Shared Decision-Making and Government Prevention Guidelines: Evolution, Implications, and Impediments," *Journal of Law, Medicine & Ethics* 49, no. 3 (2021): 444-452.
2. M. Kunneman, V.M. Montori, A. Castaneda-Guarderas, and E.P. Hess, "What Is Shared Decision Making? (and What It Is Not)," *Academy of Emergency Medicine* 23, no. 12 (2016): 1320-1324, doi: 10.1111/acem.13065.
3. N.P. Tamirisa, J.S. Goodwin, A. Kandalam, et al., "Patient and Physician Views of Shared Decision Making in Cancer," *Health Expect* 20, no. 6 (2017): 1248-1253, doi:10.1111/hex.12564; N. Singh Ospina, K.A. Phillips, and R. Rodriguez-Gutierrez, et al., "Eliciting the Patient's Agenda- Secondary Analysis of Recorded Clinical Encounters," *Journal of General Internal Medicine* 34, no. 1 (2019): 36–40, *available at* <https://doi.org/10.1007/s11606-018-4540-5> (last visited July 20, 2021).
4. M. DeCamp, D. Pomerantz, K. Cotts, E. Dzeng, N. Farber, L. Lehmann, P.P. Reynolds, L.S. Sulmasy, and J. Tilburt, "Ethical Issues in the Design and Implementation of Population Health Programs," *Journal of General Internal Medicine* 33, no. 3 (2019): 370-375, doi: 10.1007/s11606-017-4234-4.

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