

A call for community-shared decisions

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Introduction

Shared decision-making in medicine is widely viewed as a collaboration between the patient and the clinician. For example, Montori *et al* state, 'The patient and clinician must collaborate to arrive at a useful formulation of the problem'.¹ Patients are encouraged to evaluate care choices in light of the benefits and harms of each, state their preferences and identify the best course of action along with their doctor.² Despite its broad reach, shared decision-making solely between a patient and doctor has clear limits. Over 30 years ago, Brock and Wartman cautioned that '[p]atients do not have an unqualified right to make even rational individual choices that risk serious harm to others'.³ Elywin *et al* noted that 'limits on shared decision-making will occur when... wider interests overrule individual wishes'.⁴ These authors lay out problems with shared decisions for antibiotics, opioids and vaccine hesitancy. A crucial gap is how to address these problems in practice.

Antibiotic-resistant bacterial infections, overdoses from diverted opioid pills and the resurgence of measles are all medical problems that affect an individual through actions others in the community have taken. Here cooperation has either failed or has not been attempted at all. Lack of cooperation occurs when individuals believe it is in their best interest to deviate from the action that they would like others to take.⁵ While various forms of cooperative behaviour exist in the wild (eg, a large number of individuals choose to recycle, vote, tip at restaurants and donate to charity),⁵ there are barriers to cooperation in medicine that require special attention. Two of the biggest barriers are a lack of awareness that cooperation is needed and the implementation of approaches to encourage cooperation.

To address barriers, community members benefit from working towards a resolution on a *common strategy that each will follow* so that each will benefit. Reaching this resolution is a 'community-shared decision'. The common strategy involves agreeing on changes to the clinical environment that will persuade individuals to behave cooperatively. Preferably, the common strategy would encourage cooperation while maintaining freedom of choice so that individual preferences are respected. A community-shared decision carries a different relationship to value than does a standard medical-shared decision.

In a standard shared-medical decision, we must elicit preferences to understand value. In contrast, there are clear objectives for community-shared decisions that will increase value for the decision-maker. We know that if others increase their antibiotic use, our value goes down because our own chances of successful treatment decrease. We also know that if vaccination among others increases, our own values go up, since our own chance of avoiding disease exposure increases. What matters most from a value standpoint is that we all adopt a shared strategy to realise benefits and prevent losses.

Example: antibiotic overuse and vaccines

The problem of antibiotic overuse represents a 'tragedy of the commons': persons are given access to a common resource, act in their own interest and over time deplete the resource, making themselves and everyone else worse off.⁶ Perhaps because of risk aversion, patients and doctors may choose antibiotic therapy when a bacterial infection is possible but unlikely. If this is the favoured choice, antibiotic-resistant bacteria will develop from overuse.⁷ To conserve antibiotic effectiveness, everyone would benefit from fewer prescriptions at visits where antibiotics are least likely to help. In a community (hospital system, town, city, State, etc), the question we ask is 'What shared strategy will curtail unnecessary antibiotic prescriptions?' There are national goals to reduce ambulatory antibiotic prescriptions⁸ and a considerable literature on effective approaches to encourage judicious use of antibiotics that respect individual choice;⁹ most strategies involve either providing performance feedback to clinicians or making changes to how choices are presented in the electronic health record. However, the adoption of strategies to reach these goals has been carried out piecemeal and has thus far not been community-led.

The previous example discusses a public harm, antibiotic overuse. But, what about a public good such as vaccination, where the population is divided among vaccine-hesitant individuals, those who consistently do or do not get vaccinated and those who may need a gentle nudge? Standard shared decision-making here suffers from a 'free-rider' problem: hesitant patients may forego vaccination because they believe they will benefit from the vaccination of others while avoiding the perceived costs of vaccination to themselves. These individuals

favour community immunity but may fear personal risks of adverse side effects or prefer to avoid the cost and inconvenience of getting vaccinated. Here again, there is a robust literature on how to change vaccination behaviour.¹⁰ Yet, communities in partnership with health payors and local health systems have rarely adopted these strategies to improve community immunity.

Other examples

Sharing a decision with the community is needed in other instances. Choosing low-value care impacts rapidly rising healthcare costs, while communities have an interest in keeping medical premiums low. Likewise, the community has a shared interest in reducing medical decisions with iatrogenic consequences such as the opioid crisis, rising deaths from benzodiazepines and amphetamine overprescription.¹¹ Prescribers must both consider how these scheduled drugs affect their patient and also how unused drugs enter the overall 'ecosystem' as a source of abused and diverted pills. Finally, racial and ethnic healthcare equity is a community issue. A goal of reducing disparities confers benefits both to those who get care (patients) and those contemplating seeking care (community members) who either trust or do not trust the facility. Recent efforts to institute performance-based contracts that reward physicians for equitable care are laudable.¹² However, there are many other ways to deliver encouragements. Community member involvement is needed. **Box 1** illustrates two example cases.

Implementation of a community-shared decision: formalising the community's role

Over the past 30 years, there has been a strong push to abandon paternalism in medicine and engage patients in their own care. In contrast, efforts to engage communities have been minimal. Most initiatives have created opportunities for patients to express their own point-of-view to the community.¹³ Yet, as we have argued, patient-centred values fail to address the tragedy of the commons and the free-rider problem. Other approaches are needed.

A limited infrastructure presently exists for community-shared decisions. In the UK, Community Engagement Boards and Neighbourhood Health Councils have been used to various degrees and would provide a structure for the adoption of shared strategies. In the USA, community members are consulted on waivers of consent in emergency medicine research, but rarely elsewhere.¹⁴ A selection process for advisory committees should be transparent and the ultimate sampling should be as representative as possible of community demographics. Moreover, because there is always a concern that industry stakeholders may try to capture the process, outside auditors should be engaged to report on the fairness of the selection of community members and the proceedings. Once a policy is finalised, hospitals and clinics will benefit from reporting community-based decisions publicly. Patients and doctors then would understand that the local community supports a best practice.

Illustrating community-shared decisions: opioid prescribing

Given that excess opioid pills drive the misuse of opioids, a community-shared decision to limit default postoperative opioid quantities offers a valuable example of a community-shared decision. At a civic event, representatives of a hospital or health system might disclose current and target prescribing postoperation. Community members would learn about the prior default performance, how defaults do not limit physician discretion and any effects on patient safety. Community members could voice any concerns or express support. Public comments would inform a final decision made by the hospital. We believe that this public

Box 1 Case studies

The first case addresses the Tragedy of the Commons with respect to opioid prescribing. The second case addresses the free-rider problem with respect to measles. In both cases, the core approach is for the health systems to listen and respond to community needs by adjusting their own care practices.

Case 1: 2022 CDC outpatient opioid prescribing guidelines: the Tragedy of the Commons

The 2022 CDC opioid guideline removed the dose and duration thresholds from prescribing recommendations in favour of traditional shared decision-making between patients and clinicians. This approach may have unintended consequences. It may increase the circulation of opioids in an entire community and lead to harm. To engage the community to build community safety rails around these deregulations, a hospital system following our proposed approach would establish protocols to facilitate community-based decision-making that include the following:

⇒ community shared decisions regarding care approaches described in the literature,¹⁸ such as follows:

Involving the patient's family in discussions in dosing considerations for long-term opioid therapy.

Prioritise assessment role function and discourage a unitary focus on pain intensity. Develop decision aids based on community-based preferences to promote evidence-based decision-making around pain treatment.

Prioritise evidence-based non-pharmacological therapies like physical therapy, yoga, cognitive-behavioural therapy and mindfulness training. Provide education to community boards, patients and families that promote broader treatment goals beyond immediate pain relief.

Case 2: Measles vaccination policies: the free-rider problem

In 2016, Senate Bill (SB277) in California became law, removing personal belief as an exemption from childhood vaccination after rates of vaccinations fell at many schools and outbreaks were observed. However, recent studies found a countervailing increase in medical exemptions, many inappropriate, that almost completely offset the removal of the personal belief exemption.^{19 20} To ensure community-shared decisions that avoid the free-rider problem hospitals and clinics would develop appropriate education and risk assessment tools for a community board to enable meaningful input on how vaccination exemptions should be handled and what interventions might be appropriate given community risks and resources. These might include the following:

⇒ Independent physician review and approval of exemptions by the medical or community board.
 ⇒ Quality incentives for physicians.
 ⇒ Up-to-date local school vaccination rate information at the point of care.

Continued

Box 1 Continued

⇒ Decision prompts such as justifications that go in the medical record may engender reputational concerns if no good justification is given.

process would strengthen resolve and better justify clinical policies.

As noted earlier, changing the architecture of choices can improve community welfare. Community-shared decisions for default choices have been quite successful outside of medicine. For example, communities in California have been engaged in decisions for the default purchase of green energy.¹⁵ While each consumer benefits from a lower utility bill that comes with purchasing 'grey energy' that has a higher carbon footprint, there has been a realisation that a community-shared decision to reduce the carbon footprint for each consumer will have benefits for all.¹⁶ Communities are consulted on plans to switch consumers to default purchase of green energy at a slightly higher cost per consumer, though consumers can opt out of the default. A community adopting such a plan understands that this was a community-shared decision. Organ donation defaults provide a medical model for this approach.

Legislative support for community-shared decisions

There is an existing incentive for many health systems to be engaged in community-shared decisions, because they fall within the hospital community benefit requirement. Two-thirds of US hospitals are not-for-profit and are required to adhere to such a standard. The IRS Charitable Hospital Requirement states that ...

it's not enough for a hospital to state that it operates exclusively to promote health. A hospital must also demonstrate that it operates to promote the health of a class of persons that is broad enough to benefit the community. This is known as the community benefit standard.

The Affordable Care Act requires not-for-profit hospital systems to conduct a 'community needs assessment' every 3 years. These involve stakeholder meetings, focus groups with members of the community, surveys and population health data collection. A community-shared decision-making agenda should be part of community needs assessments. In particular, we imagine a goal to obtain broad public support for specific initiatives that address community health issues such as vaccination, opioid and antibiotic stewardship and efforts to eliminate low-value care.

Measuring benefit

If benefits conferred to the community derive from changes to practice, then this social surplus should be measured. Regrettably, policymakers often resort to using aggregate individual health outcomes as primary measures.¹⁷ While the patient experience is an important component of any care decision, when benefit accrues to the entire community, other approaches are needed. As we have noted, a cooperative goal is achieved when each individual chooses the action that they would like others to take.⁵ Measurement should answer if a change in medical practice relating to the cooperative goal actually took place such number of diverted pills, wastewater samples of viral concentration after vaccination campaigns, or local rates of antibiotic-resistant bacteria cultured in laboratories. Health outcomes play a secondary role in ensuring patients are not harmed.

Recommendations

We make four key recommendations. First, each healthcare system should have a protocol for meaningful public participation in care decisions that affect its broader community of stakeholders. This may involve community health councils composed of representative community samples working with medical and health professionals to identify changes to the clinical environment that may improve individual outcomes by promoting cooperation. Second, hospital community benefit plans should encourage medical decisions that will have a community benefit. Such encouragements should include a plan for increasing the uptake of medical practices or quality objectives that positively impact the community (eg, higher vaccination rates, more cost-effective healthcare, lower rates of community addiction and less proliferation of superbugs). This may include restriction of services that prevent community harm and efforts to address health inequalities in the treatment of community members. Third, community initiatives should be followed up with measures of community risk reduction (eg, reduction in hospital-acquired infections, wastewater samples for viral concentration, resistant cultured bacteria and excess scheduled drug supply in households). Fourth, the engagement of insurers with an active market presence in the community is needed to discourage low-value care and iatrogenic consequences of care in the community.

Conclusion

While most decisions in medicine are best resolved exclusively between the patient and the clinician, many are not. For some decisions, if each person takes the action that they want others to take, this can improve health for all. Community engagement in shared decisions for these problems may have benefits. It may also clarify for clinicians and patients their role in the decision. When the community has decided on cooperative action, patients and clinicians may be less resistant to quality improvement interventions, less likely to perceive an initiative as an 'encroachment' on their decision-making, and more comfortable and more agreeable to change.

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