

Physicians as Part of the Solution? Community-Based Participatory Research as a Way to Get Shared Decision Making into Practice

Stuart W. Grande, MPA, PhD¹, Marie-Anne Durand, CPsychol, PhD², Elliott S. Fisher, MPH, MD³, and Glyn Elwyn, FRCGP, PhD^{1,3,4}

¹The Dartmouth Center for Health Care Delivery Science, Dartmouth College, Hanover, NH, USA; ²Department of Psychology, University of Hertfordshire, Hatfield, UK; ³The Dartmouth Institute for Health Policy and Clinical Practice, The Geisel School of Medicine at Dartmouth College, Lebanon, NH, USA; ⁴The Cochrane Institute for Primary Care and Public Health, Cardiff University, Cardiff, UK.

Although support among policy makers and academics for the wide scale adoption of shared decision making (SDM) is growing, actual implementation is slow, and faces many challenges. Extensive systemic barriers exist that prevent physicians from being able to champion SDM and lead practice change. In other areas of public health where implementation has been a challenge, community-based participatory research (CBPR) has effectively engaged resistant stakeholders to improve practice and the delivery of care. Might CBPR, defined broadly as research that engages participants in the conception, design, and implementation of relevant health programs, be a more effective way to engage physicians, patients, and managers in the implementation process? Consequently, we argue that adopting a participatory approach may help to overcome recognized barriers to progress in this area.

KEY WORDS: shared decision making; community-based participatory research; implementation; patient engagement; clinical practice.

J Gen Intern Med 29(1):219–22

DOI: 10.1007/s11606-013-2602-2

© Society of General Internal Medicine 2013

INTRODUCTION

Shared decision making (SDM) is being widely advocated as a means to improve patient engagement in health care.^{1,2} Yet, despite the high level of interest among policy makers, the challenge of how to promote and implement SDM into routine care remains unsolved.^{3–5} Seen by many as the pinnacle of patient-centered care, SDM is a process in which physicians and patients collaborate, using the best available evidence, in order to make informed treatment decisions.

For more than a decade, advocates have sought to implement SDM into routine clinical practice, and yet, practical progress has been slow.⁶ There are some notable examples where organizations have implemented video and text-based patient decision support interventions as a way of operationalizing SDM. Among these are the work done by the SDM Center at Dartmouth-Hitchcock⁷ and the recent report of similar tools being used for surgical conditions at Group Health, Seattle.⁸ Importantly, the effect of making these tools available to patients does not, alone, equate with conducting shared decision making in practice. Indeed, a recent systematic review of attempts to introduce these types of tools finds that clinicians are reluctant to use them, making it challenging to introduce innovative tools into current health care systems.⁵ It is possible that traditional decision support interventions, such as those used primarily outside the clinical encounter, have more trouble fitting into current workflows, while the effectiveness of more innovative methods, developed for use inside the clinical encounter, remains unconfirmed. Adding to the challenge is the lack of incentives, either extrinsic (payments or performance reports) or intrinsic (enhanced status or esteem), to support the adoption of these approaches. In fact, undertaking SDM may lengthen clinical encounters, or lead to potential loss of fee-for-service if patients decline procedures, issues that physicians may view as barriers. Patients also report a fear that physicians react negatively to individuals who ask questions or voice personal preferences.⁹ In summary, many practical obstacles face those who wish to implement SDM into practice.

Lessons from Kurt Lewin's field theory and Paulo Freire's community-based learning have shown that public health interventions are most effective when developed and implemented in partnership with communities, rather than when imposed on them.¹⁰ Similar patterns are observed when efforts are made to introduce decision support tools without the full engagement of relevant stakeholders. Could it be that the goal of bringing patients and physicians together might be enhanced if proven methods of community engagement can be harnessed to help overcome the resistance to SDM? Moreover still, could these participatory methods be used to further assess collaborative tools inside the clinical encounter?

Received February 13, 2013

Revised July 2, 2013

Accepted August 16, 2013

Published online September 4, 2013

COMMUNITY-BASED PARTICIPATORY RESEARCH—A POTENTIAL SOLUTION

The resistance of physicians and others in multidisciplinary teams may be analogous to the suspicion and mistrust felt by underserved and minority communities when confronted by researchers wielding “another good idea.” Given the many challenges facing physicians, adding one more good idea (SDM), which proposes to alter patient–physician relationships, could easily trigger resistance similar to that observed in underserved communities. These communities are the typical focus of community-based participatory research (CBPR), a well-recognized method that excels in the conception, design, and deployment of culturally appropriate public health interventions, and might be helpful to those who advocate SDM.

A review of CBPR studies reported that when communities initiate activities, individuals are more likely to participate, take action to find solutions, and build leadership skills.¹¹ Given the success of CBPR methods to reduce disparities,¹² organizations like the National Healthy Start Program (NHSP) have welcomed CBPR as a useful model for organizational empowerment among diverse stakeholders in settings where recognized methods for evaluation and program design have previously fallen short.^{13,14} Might a CBPR approach, fostering a co-developed rather than an imposed solution, overcome perceived barriers to the adoption of SDM? An example of one such co-developed solution could be a decision support tool that serves the needs of the patient and physician by promoting collaboration within the clinical encounter rather than outside it. Two examples of these types of tools are Option Grids¹⁵ and Issue Cards.¹⁶ Also, might CBPR foster mutual understanding of the unique challenges faced by physicians and the fears felt by patients?

BARRIERS TO INNOVATIVE IMPLEMENTATION

We could not identify examples where SDM advocates embrace a CBPR approach or where CBPR overcomes payment system barriers. Much more is known about the barriers to SDM implementation. According to physician reports, practical issues such as time constraints and clinical resistance make SDM too intrusive to be useful.¹⁷ Additionally, physicians suggested that tools to promote SDM in the clinical encounter were not relevant to individual patients.^{3,17} Additional factors contributing to physician resistance include: peer groups, organizational influences, and informational overload. Increased patient expectations are also important—ranging from growing demand for more information to better engagement in decision making.¹⁸ At the same time, many patients feel reluctant to adopt assertive roles, lest they be regarded as adversarial.⁹

Traditionally, communities have been viewed as being composed of neighborhoods, many of which have been marginalized or underserved, and are thus suspicious of researchers’ intent. It is possible to consider health care institutions and those within them as communities where the principles of consultation, engagement, and co-production could be equally valuable. An example of a health care institution as a community with multiple stakeholders may be a hospital, where patients have unmet needs and physicians and others can’t meet growing institutional and patient demands. In the context of CBPR applied to SDM, we choose to define the term community as patients, physicians, and managers working together to make SDM a part of routine care. We believe the time is right for physicians to learn how CBPR might overcome barriers to SDM implementation. In the discussion that follows, we explore this issue to stimulate further conversation around the potential contribution of CBPR.

Table 1. Potential Contribution to the Implementation of SDM

| Contribution of the community-based participatory research (CBPR) approach * | How CBPR might help the implementation of SDM in clinical settings |
|--|--|
| <p>The effects of a leveling approach</p> <ul style="list-style-type: none"> • Equity of power: community members are assumed to have an equal footing • Equity of contribution: all members get a chance to contribute and comment | <ul style="list-style-type: none"> • Bring patients, physicians, and managers to the same table • Foster equal contribution to the agenda, shaping the implementation plan and process • Generate collaboration that leads to joint learning and ownership |
| <p>The effects of co-leadership</p> <ul style="list-style-type: none"> • Idea generation: joint-deliberation may lead to innovation or the formation of new processes and alliances • Co-learning: as knowledge is shared, attitudes shift and the potential for shared beliefs and expectations is increased | <ul style="list-style-type: none"> • Ensures that patients, physicians, and managers view leadership as shared • Greater likelihood that meetings will be held at times and locations that are accessible to wider stakeholder groups • Increased chance that the responsibility for success (and failure) will be shared more widely, i.e., team-based |
| <p>The impact on sustainability</p> <ul style="list-style-type: none"> • Alignment: implementation is more likely to be aligned to stakeholder needs and requirements • Embedded into organizational cycles: jointly developed plans and processes are more likely to be part of planned financial budgets | <ul style="list-style-type: none"> • Greater likelihood that patients, physicians, and managers regard the process as meaningful and rewarding, and not as a ‘short term’ project. • Higher chance that success will become a priority for those engaged in the work and therefore part of a positive effort |

* Modified from Israel;²⁶ Wallerstein & Duran²⁵

OUTLINING THE POTENTIAL CONTRIBUTION OF CBPR

CBPR succeeds by developing relationships that strengthen rapport and trust with communities, recognizing the value of context and culture, and empowering participants to identify and overcome barriers to implementation. The Community Action Against Asthma (CAAA) project successfully applied a CBPR approach to overcome significant systemic barriers affecting the health status of children. Bringing together multiple community organizations, academic institutions, a service-agency, a state agency, and a community member,¹⁹ CAAA implemented a research program that was both acceptable to the community and effective in reducing the burden of asthma in the community. Researchers at UCLA have successfully partnered physicians and communities through the Community Health Improvement Collaborative using a modified CBPR approach to promote, improve diabetes prevention and management and engage the community in depression care.²⁰ A recent systematic review of CBPR methods provided an interactive logic model that profiled the available evidence about how the method achieved its impacts.²¹ Evidence showed that CBPR successfully linked communities with campuses (i.e., research institutions) and served as a useful example for hospital and health organizations seeking collaboration with both local communities and research institutions.²² A study of self-care dialysis found that care pathways were easier to implement and more effective when patients were included in the development of the implementation approach.²³ We also know that when physicians partner with clinical staff to shape care pathways, and implementation strategies are tailored to physician routines, long-term sustainability of interventions is more likely.²⁴

Table 1 outlines how a CBPR approach might help the implementation of SDM in clinical settings. Three major mechanisms appear to be important:

- 1) **Leveling:** By *leveling* the dialogue among stakeholders, rather than imposing an external solution, we suggest that those who want to introduce SDM should first acknowledge the “expertise” of patients and physicians. This is possible by fostering their equal contribution and shaping design and implementation in order to generate collaboration, joint learning, and ownership.
- 2) **Co-leadership:** Requiring *co-leadership* would ensure that patients, physicians, and managers would be more likely to collaborate in planning meetings, convened at times and locations accessible to wider stakeholder groups.
- 3) **Impact on Sustainability:** When stakeholders collaborate at all stages of development, *sustainability* is more likely to support a process that patients, physicians, and managers regard as meaningful and rewarding. A commitment to engaging those affected by process changes increases the likelihood that success will become a priority for those engaged in the work.

CONCLUSION

Perhaps SDM advocates have focused too narrowly on research goals, and have not included stakeholders with the most leverage to modify how clinical systems operate—i.e., patients, physicians, and managers. We think the time is ripe to adopt a more collaborative approach. Before this can happen, all stakeholders must openly confront the many real barriers to implementation, at the organization, practice, and patient–physician level, so that those who have the most insight and potential impact are engaged to find solutions.

The Institute of Medicine (IOM) has led the way by asking for CBPR to be a new competency for all health professional students,²⁵ and the Patient Centered Outcomes Research Institute (PCORI) has clearly laid out the challenge to include relevant stakeholders as part of good practice. We feel the time is right to ensure that physicians and others are seen as part of a participatory solution, rather than as barriers to progress.

Conflict of Interest: The authors declare no conflict of interest.

Corresponding Author: Glyn Elwyn, FRCP, PhD; The Dartmouth Center for Health Care Delivery Science, Dartmouth College, 37 Dewey Field Road, Hanover, NH 03755, USA (e-mail: glynelwyn@gmail.com).

REFERENCES

1. Barry MJ, Edgman-Levitan S. Shared decision making—the pinnacle of patient-centered care. *N Engl J Med*. 2012;366(9):780–781.
2. Oshima Lee E, Emanuel EJ. Shared decision making to improve care and reduce costs. *N Engl J Med*. 2013;368(1):6–8.
3. Légaré F, Ratté S, Gravel K, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions. *Patient Educ Couns*. 2008;73(3):526–535.
4. Elwyn G, Grande S, Gittel J, Godfrey M, Vidal D, eds. Are we there yet? Case studies of implementing decision support for patients. Hanover: Trustees of Dartmouth College; 2013:135.
5. Elwyn G, Scholl I, Mann M, et al. The implementation of patient decision support interventions into routine clinical practice: A systematic review. *BMC Med Inform Decis*. 2013;In Press.
6. Légaré F, Witteman HO. Shared decision making: Examining key elements and barriers to adoption into routine clinical practice. *Health Affair*. 2013;32(2):276–84.
7. Collins ED, Moore CP, Clay KF, et al. Can women with early-stage breast cancer make an informed decision for mastectomy? *J Clin Oncol*. 2008;27(4):519–25.
8. Arterburn D, Wellman R, Westbrook E, et al. Introducing decision aids at Group Health was linked to sharply lower hip and knee surgery rates and costs. *Health Affair*. 2012;31(9):2094–2104.
9. Frosch DL, May SG, Rendle KA, Tietbohl C, Elwyn G. Authoritarian physicians and patients' fear of being labeled “difficult” among key obstacles to shared decision making. *Health Affair*. 2012;31(5):1030–8.
10. Faridi Z, Grunbaum JA, Gray BS, Franks A, Simoes E. Community-based participatory research: Necessary next steps. *Prev Chronic Dis*. 2007;4(3):A70.
11. Cook WK. Integrating research and action: A systematic review of community-based participatory research to address health disparities in environmental and occupational health in the USA. *J Epidemiol Commun H*. 2008;62(8):668–76.
12. Israel BA, Coombe CM, Cheezum RR, et al. Community-based participatory research: A capacity-building approach for policy advocacy

- aimed at eliminating health disparities. *Am J Public Health*. 2010;100(11):2094–102.
13. **Minkler M, Blackwell AG, Thompson M, Tamir H.** Community-based participatory research: Implications for public health funding. *Am J Public Health*. 2003;93(8):1210–3.
 14. **Minkler M, Thompson M, Bell J, Rose K.** Contributions of community involvement to organizational-level empowerment: The federal healthy start experience. *Health Educ Behav*. 2001;28(6):783–807.
 15. **Elwyn G, Llyod A, Joseph-Williams N.** Option Grids: Shared decision making made easier. *Patient Educ Couns*. 2013;90(2):207–212.
 16. **Montori VM, Breslin M, Maleska M, Weymiller AJ.** Creating a conversation: Insights from the development of a decision aid. *PLoS Med*. 2007;4(8):e233.
 17. **Caldon LJM, Collins KA, Reed MW, et al.** Clinicians' concerns about decision support interventions for patients facing breast cancer surgery options: Understanding the challenge of implementing shared decision-making. *Health Expect*. 2011;14(2):133–46.
 18. **Grimshaw JM, Eccles MP, Walker AE, Thomas RE.** Changing physicians' behavior: What works and thoughts on getting more things to work. *J Contin Educ Health Prof*. 2002;22(4):237–43.
 19. **Parker EA, Israel BA, Robins TG, et al.** Evaluation of Community Action Against Asthma: A community health worker intervention to improve children's asthma-related health by reducing household environmental triggers for asthma. *Health Educ Behav*. 2008;35(3):376–95.
 20. **Jones L, Wells K.** Strategies for academic and clinician engagement in community-participatory partnered research. *J Am Med Assoc*. 2007;297(4):407–10.
 21. **Sandoval JA, Lucero J, Oetzel J, et al.** Process and outcome constructs for evaluating community-based participatory research projects: A matrix of existing measures. *Health Educ Res*. 2011;27(4):680–90.
 22. **Seifer SD, Blanchard LW, Jordan C, Gelmon S, McGinley P.** Faculty for the engaged campus: Advancing community-engaged careers in the academy. *J High Educ Outreach Engagem*. 2012;16(1):5–20.
 23. **McLaughlin K, Manns B, Mortis G, Hons R, Taub K.** Why patients with ESRD do not select self-care dialysis as a treatment option. *Am J Kidney Dis*. 2003;41(2):380–5.
 24. **Grol R, Wensing M.** What drives change? Barriers to and incentives for achieving evidence-based practice. *Med J Aust*. 2004;180(6 Suppl):S57–60.
 25. **Wallerstein N, Duran B.** Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity. *Am J Public Health*. 2010;100(Suppl):S40–6.
 26. **Israel BA, Schulz AJ, Parker EA, Becker AB.** Review of community-based research: Assessing partnership approaches to improve public health. *Annu Rev Public Health*. 1998;19:173–202.