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PEER-REVIEWED CME ARTICLE: STATE OF THE ART AND SCIENCE

Social Media Channels in Health Care Research and Rising Ethical Issues

Samy A. Azer, MD, PhD, MEd, MPH

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Abstract

Social media channels such as Twitter, Facebook, and LinkedIn have been used as tools in health care research, opening new horizons for research on health-related topics (e.g., the use of mobile social networking in weight loss programs). While there have been efforts to develop ethical guidelines for internet-related research, researchers still face unresolved ethical challenges. This article investigates some of the risks inherent in social media research and discusses how researchers should handle challenges related to confidentiality, privacy, and consent when social media tools are used in health-related research.

Introduction

The three most commonly used social media websites are Twitter, Facebook, and LinkedIn [1-3]. These increasingly popular social networking sites are used by the public, professionals, and students to gather and share information. Among internet users in the United States, approximately 78 percent used social networking sites in 2016 [4], and the sharing of information on these networks is changing communication patterns [5]. Accordingly, social media websites are becoming valuable research tools, particularly in the area of health care [6].

Social media channels offer a number of opportunities for researchers to initiate studies on:

- The impact of social networks on perceived social support (e.g., of patients with chronic diseases) [7]
- How social media users gather and exchange health-related information and share personal experiences [8-10]
- The spread of misinformation about disease outbreaks to inform public health communication strategies [11]
- Recruiting patients in clinical trials [12, 13]

- The effect of social network media exposures on certain behaviors [14]
- The spread of public health-related information (e.g., cancer awareness) and the prevalence of certain behaviors (e.g., opioid misuse) [15-17].

Thus the use of social media websites as research tools can bring new insight and possibly enhance understanding of how health-related communities meet different needs [18].

Given the potential of social media websites as research tools, this article aims to investigate some of the associated risks and to discuss how researchers should handle these challenges when designing their research. This article particularly addresses confidentiality, privacy, and consent as they apply to internet research as well as ethical issues specific to social networking sites.

Social Media Websites and Ethical Challenges

While one may argue that regardless of the design and purpose of social media websites (channels) all information conveyed through social media should be considered public and therefore usable in research, such a generalization is incorrect and does not reflect the principles we follow in other types of research. The distinction between public and private online spaces can blur [19], and in some situations it is difficult to draw a line. Moreover, as discussed later, social media channels operate under different rules than research, and thus using these tools in research may raise a number of ethical concerns, particularly in health-related research [20, 21]. Good research practice fortifies high-quality science; ethical standards, including integrity; and the professionalism of those conducting the research. Importantly, it ensures the confidentiality and privacy of information collected from individuals participating in the research [22]. Yet, in social media research, there are challenges to ensuring confidentiality, privacy, and informed consent.

Privacy. Compared to face-to-face encounters, social media connections erase any geographical boundaries and make social cues of limited use. Depending on users' privacy settings, their personal profiles may be exposed to other users from other cultures, communities, and different walks of life who are included in the social network but are not known to them. Users might not even trust the other users who can view their profiles if they became aware of their connection. These automatic exposures inherent in social media networks arguably represent a real concern in regard to privacy [23]. For example, Facebook's privacy settings are problematic because they are opaque and dependent on the user's self-education.

The concern about privacy is not just hypothetical. Researchers from the University of Otago Medical School in New Zealand surveyed young medical graduates regarding their use of Facebook; they found that a quarter of the doctors in the sample did not use the privacy options, rendering the information they revealed readily available to the wider public. As a result, they could violate the professional boundary between them and their patients (for example, by posting photos of their admitted patients without obtaining their permission) [24]. While this study does not represent Facebook users as a whole, it does raise the important point that users might not be aware of or concerned about the privacy of their personal information on social media. The privacy options might not be protective as users think; the options provided by Facebook do not guarantee full privacy [25]. The limitations in the system design could also pose challenges for researchers attempting to obtain valid consent.

Consent. Joining a Facebook group gives permission to the entire group to access one's own information. Therefore, when friends join a Facebook group, they become able to access information available from all the others in the group [23]—for example, a researcher can examine medical interns' adherence to professional behavior by monitoring their posts and activity. Using social media channels in research allows researchers to access and engage with network members without using mechanisms that ensure that consent is truly informed or provided [26].

The ethical problems associated with this practice are exemplified in a study that provided experimental evidence of the massive scale of emotional contagions propagated through the use of social media networks [27]. The paper received extensive publicity because of the method used. The experiment involved manipulating Facebook users' newsfeeds, but the participants were not aware of their involvement in the research experiment and were not asked to give informed consent. The paper was published in the *Proceedings of the National Academy of Sciences of the United States of America* (*PNAS*) in 2014. The editor of the journal wrote an editorial defending the journal's decision to publish it, stating, "The authors noted in their paper, '[The work] was consistent with Facebook's Data Use Policy, to which all users agree prior to creating an account on Facebook, constituting informed consent for this research'" [28]. Interestingly, the editor was aware from the corresponding author's submission that the work "was conducted by Facebook, Inc. for internal purposes" and that for this reason, the institutional review board at Cornell University, where the authors work, "determined that the project did not fall under Cornell's Human Research Protection Program," which did not consider the project for ethical evaluation [28]. The editor aimed to justify the journal's decision to accept the paper for publication in *PNAS* without its being ethically approved by an institutional ethical review body by explaining that the Common Rule (i.e., federal human subjects protections) does not preclude the use of data collected by a private company such as Facebook [28].

Although the research was arguably unlikely to cause harm and the design helped the authors to come up with strong evidence for their research, scholars raised significant concerns about such a move. For example, Kleinsman and Buckley argued that the research was not ethical because it should have been overseen by an independent review body or ethical committee, and informed consent should have been obtained from participants [29]. This example thus shows that there are different views about ethical concerns in relation to the use of social media in research.

Specific Ethical Concerns in Health-Related Research

In social media research, participants can be identified either directly or through the internet links related to the websites used, which arouses concerns about the definition of privacy in social media research and the need to evaluate each research study in context and on its own merits [30-34]. Therefore, if the study enables the disclosure of subjects' responses or statements in a way that might reveal their identity or their place of residence or that exposes them to risks or potential harms (e.g., political, financial, social)—such as research using videos from the war in Syria—it must be approved by an institutional ethical research review committee. The risk in these situations is directed to a particular subject or a group of people whose identity is revealed through social media research [18, 35].

Other factors that should be taken into consideration in assessing a research project that uses social media websites may include the following:

- *The regulations and policies of the institutional ethical research review committee*. Universities vary in their regulations regarding ethical approval of research. For example, some universities in Europe do not have policies regulating educational research or research covering social media. On the other hand, the ethical research review committees in other universities may require approval for any research involving social media [36].
- *The privacy statements of the social media websites (e.g., Facebook and Twitter) used in the research, including rights and responsibilities* [37, 38].
- *The level of privacy in the settings offered by the social media website (e.g., Facebook).* The Facebook profile security settings allow information to be shared to the public or only to friends. Such a system can limit the exposure of postings to the public. However, as stated earlier, any friend joining a group because he or she was accepted by one member in the group could look at the Timeline of others and receive such information. Many users do not even know how to use Facebook's privacy settings. In YouTube, the video privacy settings are different [39], and many videos on YouTube can be seen by and shared with anyone. As the differences between Facebook and YouTube illustrate, privacy measures vary across social media tools [40].
- *The magnitude of interaction*. Research that necessitates interaction with members on a social media website should not be considered a low-risk project, and in the author's view, approval from an ethics research review committee is needed.

Recommendations

In all research that uses social media channels, researchers have to consider a number of ethical challenges that they might face. While the general principles of research apply to social media research, more attention should be given to specific issues related to social media. The following key issues should be considered as researchers prepare for using social media tools in health-related research:

1. *The use of social media in research should be justified*. Key questions that can help in reaching a conclusion about whether the research is justified are: Is social media the best tool to be used in conducting this research? And in what way is social media better than face-to-face data collection?
2. *Social networking sites should be considered private spaces, and consent to participate in research should be obtained*. Researchers should treat them as private even though they are not to ensure that privacy is maintained, particularly when subjects can be identified either directly or through the internet links related to the website included in the research. Therefore, recruitment of participants should be transparent, and there should be mechanisms by which participants can ask questions. It is important that researchers discuss consent electronically with participants before their enrollment.
3. *Researchers should outline a plan to ensure the confidentiality of data collected*. A key question is how researchers would ensure that data collected from participants is carried out on a secure site outside the social networking site. Closed forums that ensure confidentiality of discussion among participants for research purposes should be an integral part of the research design, particularly in health-related research using social media channels.
4. *Is the project a potential source of harm?* Participants are usually not aware that their contributions on social media websites are potentially accessible. Researchers have a responsibility to not directly or indirectly harm participants by what they expose in doing and publishing research. However, it may be difficult to identify "harm." Researchers have to be thoughtful about any potential harm that their research might incur by being sensitive to the content extracted from social media websites, the degree and context of content exposure, and the authenticity of the material used.

With these recommendations in mind, every research study should be evaluated on its own merits by the ethical research review committee, and recommendations should be individualized accordingly.

Conclusion

Currently, there is growing interest in using social media platforms including Twitter, Facebook, and LinkedIn in health care research. However, as shown in this article, there are emerging ethical and professional concerns and risks inherent in social media research that should be carefully evaluated and addressed—particularly regarding confidentiality, privacy, and consent. While these issues present challenges to institutional ethical research review committees and researchers, to the author's knowledge, currently no US professional societies have issued guidelines or regulations addressing these rising ethical concerns. With the growing interest in health-related research using social media, the regulation of this area should be given priority. The author has listed four recommendations to be used as guiding principles in using social media in health care research.

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Why Can't We Be Friends? A Case-Based Analysis of Ethical Issues with Social Media in Health Care, November 2015

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FROM THE EDITOR

Co-Creation in Health Systems Design

The concept of co-creation has been central to a variety of service industries for several decades. A tool to fuel innovation and customer satisfaction, co-creation acknowledges that the success of any given enterprise depends not only on the expertise, assets, and core competencies of the service provider but also on the knowledge and perspectives of the target customer as well. Co-creation extends beyond consultation with or participation of consumers. It is about integrating customers into the processes of product and service ideation and execution so that their unique perspectives and cooperation may ultimately drive value for both the producer and the customer [1, 2].

Nike® is a prime example of a company that successfully incorporates co-creation into its business model. The athletic footwear company creates online communities that serve as a vehicle for management to be apprised of the latest reactions and feedback to its products. In turn, Nike offers its customers a forum to express their experiences as well as educational resources from Nike "experts." Customers find value in the platform products and the services that connect them to users and experts, which builds trust and "stickiness," and Nike derives value from real-time feedback on products that enables more optimal redesigns [3]. Co-creation becomes a win-win for all involved, and it is thus not surprising why several industries—technology, education, retail, law enforcement, and financial services, to name a few—employ co-creation in their core practices [1].

Health care has been slow to adopt co-creation. Historically, patients have been considered passive recipients of services provided to them by those in the health care industry. The ecosystem of health care evolved relatively independently of their voices, which is contrary to the customer-provider interaction in many other industries outside of health care. However, amidst rising health care costs, growing pressures for improved quality and safety metrics, and increasing demand for more personalized care, the field of medicine would benefit by shifting away from the provider-centric model of care toward one that is more responsive to the needs of the other key stakeholder in the formula—the "consumer," otherwise known as the patient [4].

A growing body of health care literature suggests that such a collaborative approach to medicine can ultimately result in improved efficiencies and outcomes, increased patient satisfaction and trust, and greater capacity for medical research [5]. A variety of models for incorporating the patient perspective have been proposed as well. Models that engage patients as partners from the onset of service development, or those that leverage patient communities as support groups, provide frameworks that can enable the health care industry to better utilize patient perspectives. Meanwhile, patients ultimately benefit from more relevant and optimally designed services that are better tailored to their specific needs [6].

Ethical tensions can arise, however, when health care organizations try to incorporate practices of co-creation within the traditional system of health care delivery and with limited resources. Such tensions concern equitable allocation and distribution of resources, accountability of various stakeholders, and establishment of health care priorities in a complicated health care ecosystem. This issue of the *AMA Journal of Ethic*s will elaborate upon some of these tensions, but it will also examine the challenges and benefits of the co-creation process and how co-creation can be used in medicine.

Three case commentaries highlight common ethical questions that arise in implementing co-creation in practice. Matthew Kucmanic and Amy R. Sheon show how injustices that occur when patient and clinician focus groups disagree about a redesign plan can be rectified by ensuring that decision making is transparent, justifiable, and subject to review. Aveena Kochar and Alia Chisty examine how the four quality improvement principles can be used to facilitate group discussions regarding process and quality improvement within co-creative teams. And Priya Nambisan discusses managing the risk of misinformation in online patient forums as well as strategies that can help such forums achieve their full potential.

Two articles examine how co-creation intersects with medical education. Alan Cribb, John Owens, and Guddi Singh highlight that a truly collaborative health care system based on principles of co-creation depends on successfully integrating such ideals into the medical curriculum and the process of curriculum development. In a separate article, Singh, Owens, and Cribb discuss the importance of local context and transforming professional roles and power dynamics in overcoming challenges to co-creation.

Four articles examine the benefits and challenges of co-creation. Puja Turakhia and Brandon Combs call for co-creation as the next crucial step for health organizations pursuing improved outcomes, research, and safety. The remaining articles critically examine the conditions and consequences of co-creation. Sigal Israilov and Hyung J. Cho examine the barriers to co-creation posed by physician autonomy, patients' limited knowledge and expertise, and conflicts of interest. Satish Nambisan and Priya Nambisan explore policies and strategies necessary for promoting equitable distribution of the risks and benefits of technology within health care. And Brian Van Winkle, Neil Carpenter, and Mauro Moscucci explore the digital injustice to underserved populations for whom technological innovations can be ineffective.

Finally, the podcast examines the roles that design plays in co-creation. John Meyer discusses how design thinking can contribute to health care systems, beginning with its focus on the patient; Bon Ku explains how design can be incorporated into medical education; and Laura Webb shares a patient perspective about how good design can improve patients' experience with health care applications.

It is crucial that health care transitions from the traditional, paternalistic model of care to a more cooperative, transparent model that involves patient participation on multiple levels. If we are able to better navigate the challenges outlined above, we can hope to see improved levels of patient satisfaction and overall quality of care.

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ETHICS CASE

What Critical Ethical Values Guide Strategic Planning Processes in Health Care Organizations?

Commentary by Matthew Kucmanic, MA, MPH, and Amy R. Sheon, PhD, MPH

Abstract

This case explores a fictitious hospital's use of co-creation to make a decision about redesign of inpatient units as a first step in incorporating stakeholder input into creation of governing policies. We apply a "procedural fairness" framework to reveal that conditions required for an ethical decision about space redesign were not met by using clinician and patient focus groups to obtain stakeholder input. In this article, we identify epistemic injustices resulting from this process that could undermine confidence in leadership decisions. Suggestions are offered for incorporating stakeholder input going forward that address prior shortcomings. The result should be conditions that are perceived as procedurally fair and decisions that engender confidence in institutional leadership.

Case

The Moore County Hospital has been debating whether to establish its governing policies based on input from one focus group of former patients and another focus group of clinicians. Improving patients' health outcomes and satisfaction scores are particularly important goals, so the hospital's senior leadership would like to more closely integrate patients into creating organizational policies that ultimately shape their care experiences. Dr. Toftle, a physician now retired from practice whose main role is in the hospital's administration, is a facilitator for the focus groups. She is leading a team tasked with reviewing input from the stakeholder focus groups, evaluating it, and facilitating consensus among the focus groups.

Specifically, the hospital's senior leadership has budgeted to redesign the physical layout of the inpatient units, and a cross-disciplinary group of clinicians has devised a layout that they feel would promote greater efficiency and collaboration from a professional caregiver's point of view. Nurse members of the focus groups express a need to be stationed farther away from patients' rooms and closer to other members of clinical staff in a pod structure. They reference a chapter on design in the well-known book, *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*, published by the Agency for Healthcare Research and Quality [1], which describes the utility of placing nurses in separate alcoves. This kind of design enables nurses to see their patients while also helping to reduce distractions that could interfere with their work. It also would enable easy access to the supply room and other members of the clinical team—physicians, social workers, and other nurses. Most nurse members of the focus group agree that this approach to design of the pod would best enable them to carry out their daily tasks and responsibilities efficiently.

Many members of the patient focus group, who are all former patients of the hospital, oppose the pod design many of the nurses favor, however. They would prefer that nurses be as close as possible to patients' rooms. They reference the same chapter, which notes the benefits to patients of nurses' close proximity [1]. Members of the focus group of former patients favor an approach to pod design in which a patient's nurse can work at a computer unit stationed directly outside a patient's room.

This is the first time the Moore County Hospital is soliciting input from former patients, and Dr. Toftle must review the range of participants' feedback and suggest next steps for motivating consensus so that strategic planning processes can progress. The design favored by the nurses in the focus group is supported by numerous cross-disciplinary professionals within the hospital organization. The focus group of former patients is not only much smaller and less vocal but also less experienced in the day-to-day work of delivering health care to patients. Dr. Toftle wonders how to proceed.

Commentary

In this case, an administrator is seeking a consensus on the redesign of inpatient units from clinician and patient focus groups—whose members expressed conflicting preferences—as a first step in incorporating patient input into the creation of governing policies. The hospital has identified improving patient health outcomes and satisfaction scores as especially important goals for the space redesign. Dr. Toftle's search for a consensus among the clinicians and patients in the focus groups suggests that leadership sees achieving consensus as more important than the underlying health and satisfaction goals of the space redesign, which would seem to contravene a straightforward utilitarian view of beneficence that would privilege patient outcomes.

In this article, we apply Persad's "procedural fairness" framework to Dr. Toftle's and the focus groups' decision-making processes. In particular, we examine whether Dr. Toftle's and the focus groups' decisions met conditions for accountability, as well as noting epistemic injustices that resulted from Dr. Toftle's arrangement of clinician and patient focus groups. We then suggest strategies to make her decision-making process more accountable and to ensure that all voices are heard. We believe these steps will create a decision-making process that seems reasonable, fair, and ethical to stakeholders.

Procedural Fairness in Decision Making

A top-down, opaque process of decision making has traditionally been the norm in clinician-patient relationships. Thus, patients typically were unlikely to have questioned the fairness of a trusted clinician deciding what data or information to give to or withhold from them. However, experimental evidence has shown that if people lack information about the trustworthiness of an authority figure, they judge that person's decisions based on whether they believe the person used a fair process to reach the decision [2]. In the health care context, procedural fairness is sought through increasing the amount of information given to patients about the science and process behind a clinical policy or procedure, thereby fostering trust between patient and clinician [3]. In the case scenario, Dr. Toftle actively sought patient input in an effort to abrogate the typical health care information flow pattern, thereby strengthening the voices of those coming from the lowest rungs of authority. At first blush, such an arrangement might have been considered a positive and fair process, thus engendering trust in Dr. Toftle's decision. However, merely flattening the traditional hierarchy does not automatically produce a fair or trustworthy process. Input from the clinician and the patient focus groups raises a mix of value questions (e.g., patient preference for having nurses close by) and factual ones (e.g., the effect of nurses' distance from supplies on patient outcomes).

Persad [4] offers especially pertinent criteria for procedural fairness that can be applied to value-based and fact-based questions. In this case, clinician and patient satisfaction are value-based outcomes, whereas patient health outcomes and the distance of nurses to supplies are purely factual or epistemic questions. For value-based decisions, Persad relies on Daniels and Sabin's argument that decisions meeting four conditions of "accountability for reasonableness" [5] are "ethically correct regardless of the substance of the decisions themselves" [6]. These conditions include requirements for decisions to be publicly accessible (publicity condition) and justified by relevant arguments (relevance condition), to provide a means for appeal and modification (revision and appeals condition), and for the decision process to incorporate accountability for the other three conditions (regulative/enforcement condition) [4]. For decisions involving factual outcomes, Persad argues that procedures are viewed as fairer when they avoid four types of epistemic injustice: the discounting of someone's views "on the basis of unjustifiable biases" (testimonial injustice) [7], "ignoring testimony that cannot be conceptualized or expressed" within the existing framework (hermeneutical injustice) [7], "treating others as passive states of affairs" from which information is taken but not given (epistemic objectification) [7], and "using methods for collecting information that exclude relevant individuals or relevant information" (exclusion) [7].

In what follows, we apply Persad's procedural fairness framework to Dr. Toftle's and the focus groups' value-based and fact-based decisions.

Processes Required to Meet Conditions of Accountability

First we will assess the extent to which Dr. Toftle's and the focus groups' decision-making process met conditions for reasonableness.

- *Publicity condition*. More information would be needed to determine whether Dr. Toftle's decisions in convening and gaining input from the focus groups were publicly accessible, but a transparent process would involve disclosing how focus group members were selected and making available a summary of the input offered from each group.
- *Relevance condition*. Use of evidence by both focus groups seemingly was justified by relevant arguments that would be "accepted as relevant by fair-minded people who are disposed to finding mutually justifiable terms of cooperation" [8]. Nurses in the clinician group cited evidence that their preferred design, which put them closer to other staff and to supplies, enabled good visibility of patients and reduced distraction. Patients cited the same source to justify an opposing preference for nurses to be "as close as possible to patients' rooms."
- *Revision and repeals process*. To satisfy the revision and appeals process, Dr. Toftle would need to publicize a provisional design decision, seek and consider input, and then offer a final decision.
- *Regulative/enforcement condition*. To meet the regulative/enforcement condition, stakeholders would need to know who would receive Dr. Toftle's recommendation and that she would be held accountable for meeting the other conditions required for the decision process to seem reasonable and fair.

Avoidance of Epistemic Injustice

Design of the input process. Dr. Toftle set the stage for numerous forms of epistemic injustice by using a static process, convening one focus group of clinicians and one of former patients. She likely separated patients and clinicians to avoid the testimonial injustice of clinicians discounting patient views due to their unjustifiable biases (e.g., against patients' lower education levels). While focus groups benefit from homogeneity, a structure that would enable ongoing interaction between the clinician and patient focus groups would be needed to address epistemic injustices. The arrangement of noninteracting clinician and patient focus groups created an exclusion injustice whereby the clinician group may not have considered all relevant information, such as evidence for the effect of design on outcomes of interest to patients. Because the patient group lacked an individual with operational knowledge of the hospital, it sought an unrealistic level of nurse proximity that would be readily dismissed by clinicians. Patients' lack of operational knowledge could have created a hermeneutical injustice because their framework did not allow for consideration of relevant testimony from clinicians about staffing limits. This injustice possibly could have been prevented by an iterative process that might have allowed the patients to learn of actual nurse staffing levels and revise their position accordingly. In failing to provide a mechanism for feedback and revision, Dr. Toftle was guilty of epistemic objectification whereby members of the groups were treated as passive beings from whom information was gleaned.

Weighing stakeholder input. Because the patient group is described as being "smaller and less vocal" and "less experienced" in the work of delivering health care, Dr. Toftle faces several challenges in giving the patient group's viewpoint equal consideration. It would be important to know whether these "former patients of the hospital" would likely continue their relationship with the hospital or would not return due to extreme dissatisfaction with their care. Exclusion of the views of former patients who would never return would likely be an exclusion injustice, but it might also be a hermeneutical injustice if their reasons for never returning were important but only indirectly connected to the patient satisfaction issues associated with space usage. However, it is not clear that such input could be gathered fairly in a focus group that combined continuing patients with those sworn to never return. There would be an obvious risk of testimonial injustice whereby the continuing patients would be biased against the never-returning patients who might have been presumed to be using the focus group as an opportunity to air unrelated grievances. Focus groups are generally recommended to consist of homogeneous groups [9], so the hospital would have needed to conduct a separate focus group to include the views of those never planning to return for treatment.

The clinician group also had members who did not agree with the majority opinion. Failure to articulate the minority view could be a testimonial injustice if the minority views were excluded because of an unjustifiable bias, such as female nurses' bias against male nurses. Or an exclusion injustice might have occurred if the group deliberately met when members with unpopular views were unavailable.

Next Steps for Design Decision Making

To reach a decision about the hospital redesign that would be perceived as procedurally fair while honoring the input of all of the stakeholders to date, Dr. Toftle should first abandon her desire for the groups to reach consensus on fact-based and value-based questions. Citing Elizabeth Anderson [10], Persad notes that *factual* decisions become more epistemically justified when they represent a scientific consensus [4]. Were the groups to have reached a consensus that maximized patient satisfaction at the expense of patient outcomes, it would be hard to argue that the outcome was an ethical decision by Persad's criteria because satisfaction is a value-based question. Rather, Dr. Toftle must be guided by beneficence to reach a decision that optimizes outcomes over satisfaction or consensus.

Dr. Toftle should outline a longer term, transparent decision-making process that both satisfies the conditions needed for reasonableness and addresses the epistemic injustices that have already occurred. Leadership should invite nominations for a single task force comprising "fair-minded people who are disposed to finding mutually justifiable terms of cooperation" [8] and who represent the full range of relevant stakeholders. To counter the testimonial injustice of the earlier actions, Dr. Toftle should include some members from the focus groups who were observed to hold a range of views on the proposed design but were also known to be articulate, to be open to others' opinions, and to work well in a team environment. In addition, she should actively solicit feedback from focus group participants whose views are not represented in the majority opinions. The task force could either incorporate these views or explain reasons for rejecting them through published FAQs. Dr. Toftle must also anticipate that in a single task force, members lower in the medical hierarchy would remain at risk of testimonial injustice. To counter this possible injustice, she might require that all task force members undergo interprofessional or community-based participatory training, such as that offered at the authors' institution [11, 12] and has been advocated as a way of enhancing research capacity [11-13]. Such training might also reduce biases that lead to unfair exclusion of some voices.

To satisfy the publicity condition, Dr. Toftle should outline the decision-making process and provide updates through newsletters, town halls, and blogs. "Design thinking" might be an especially useful paradigm for this process [14] in that it counters epistemic objectification through a structured cycle of inspiration, ideation, and implementation that incorporates a revision and appeals condition.

To rectify the injustices that resulted from having had nonexperts interpret complex scientific literature and to better meet Persad's condition of relevance, Dr. Toftle might engage a neutral expert to summarize the relevant empirical literature. To satisfy the revision and appeals process, she should ensure that, after the space is built, a mechanism exists to obtain ongoing feedback from stakeholders so as to optimize use of space and care processes. Finally, the entire process should be approved of by senior hospital leaders, satisfying the regulative/enforcement condition.

Conclusion

By replacing the search for consensus with an ongoing transparent process, addressing the conditions of accountability for reasonableness in decision making, and addressing past epistemic injustices, Dr. Toftle should be able to reach a decision that she and the other stakeholders are confident is in the best interest of all patients and staff, rather than one that satisfies two small groups of stakeholders. Instead of presiding over a situation likely to produce winners and losers, Dr. Toftle will have created one in which everyone can feel that their voices have been heard and have full confidence in the decisions of hospital leadership.

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ETHICS CASE

What Should Leaders Do When Inefficiency Is Perceived as a Cost of Inclusivity in Strategic Planning Processes in Health Care?

Commentary by Aveena Kochar, MD, and Alia Chisty, MS, MD

Abstract

During the development of new health care policies, quality improvement teams can face the challenge of weighing differing opinions within the group that can hinder progress. It is essential in such cases to refer to the four keys principles of quality improvement (QI) as a guide to enhance group cooperation and promote development of the mutual objective. Co-production is a model that emphasizes the participation of the patient—a service receiver—in the production of services being rendered by the health care professional. By putting into practice the QI principles and using the model of co-production, quality improvement teams can improve efficiency of health systems and clinical outcomes.

Case

Dr. Stevens chairs her institution's quality improvement council, a group dedicated to implementing hospital policies and procedures that promote optimal resource utilization and best possible clinical outcomes for patients. Every month, a multidisciplinary group of clinicians and administrators meet to discuss progress of recent quality improvement efforts. A particular area of concern has to do with reducing falls among inpatients. Falls can be catastrophic for some patients and can result in increased morbidity. Once they've happened, they can be difficult and costly to manage, and they can influence reimbursement.

The quality improvement council hopes to implement and optimize fall prevention initiatives to reduce patients' risk. After several months of planning, Dr. Tarib, a hospitalist, and Mr. Collins, a nurse informaticist, propose a plan that seeks to better integrate the roles of nurses, physical therapists, occupational therapists, medical assistants, and medical students into rehabilitation programs devoted to facilitating patients' walking. A goal of this plan is to integrate effective fall prevention strategies throughout patients' rehabilitation programs.

Dr. Stevens notices that the quality improvement council represents many organizational stakeholders whose input is regarded as necessary for implementing new initiatives but does not include former patients. She has read in a recent article that patient involvement in strategic planning can contribute to improved health system efficiencies, improved health outcomes for patients, increased trust between clinicians and patients, increased satisfaction among patients, and reduced costs for health care organizations. She regards the absence of former patients' perspectives as a shortcoming in the quality improvement council's strategic planning processes. Several council members agree that former patients' views should be incorporated, and a small group of former patients who have recovered from falls in health care settings have now been invited to deliberate with the council about developing fall prevention initiatives.

Some members of the group of former patients suggest that they are not comfortable with the roles proposed for medical assistants and medical students in the fall prevention plan proposed by Dr. Tarib and Mr. Collins. While they express respect for the professional experience that informs Dr. Tarib's and Mr. Collins's fall prevention proposal, they also express suspicion about entrusting critical parts of implementing the fall prevention protocol to assistants and students. They cite their own experiences, recalling how their walking rehabilitation efforts required intense physical exertion and also aroused feelings of anxiety about how their bodies would be handled by those upon whom they depended to help them try to keep stable and upright when they felt weak and needed more help during their rehabilitation sessions.

One former stroke recovery patient says, "I relied on a masters-prepared physical therapist who understood how a body like mine could fall. She trained me in how to do these micro-movements that were critical to my progress. I just can't imagine a medical student or medical assistant having the index of experience, expertise, and patience to help me like she did. They're not trained like physical therapists at all. Why would you expose a vulnerable postoperative patient, for example, to that kind of risk? Is it to save money?"

While initially eager about welcoming former patients to the council deliberation, Dr. Tarib and Mr. Collins now feel frustrated. This former patient's comment and a few others like it during the most recent meetings of the council prompts some clinician members to complain about how former patients' participation requires longer and more frequent meetings, partly due to the need to explain clinical concepts with which clinician members of the council are already familiar and comfortable. They openly express their aggravation privately to each other and to Dr. Stevens, declaring, "The patients have raised some important points, but they don't always know what they're talking about. The conversation is now full of complexities we didn't worry about before. How will we ever come to a decision? I just can't keep taking time away from my other duties to attend meetings that are full of inefficiencies, obstacles, and questions. We're not making progress anymore."

As chair of the council, Dr. Stevens must decide what to do.

Commentary

As seen with Dr. Stevens and the quality improvement council, incorporating patients into the process of developing a new policy can be challenging and met with resistance by health care professionals who, though well-meaning, have competing interests. Moreover, time pressures often cause clinicians to revert back to traditional paternal roles. In this paper, we first examine the simultaneous development of patient-centered care and co-production to understand the centrality and importance of patient engagement to co-production initiatives. We then show that, by adopting the Health Resources and Services Administration's four pillars of quality improvement (QI)—a focus on patients, on being part of the team, on the use of data, and on quality improvement as a system and process [1, 2]—Dr. Stevens can guide the members of the group to remain true to the purpose of co-creating QI projects.

The Development of Patient-Centered Care and Co-Production

Over the last two decades, society has seen a monumental transformation in the patient-physician relationship. Traditionally, the relationship was paternalistic. Similar to the manner in which a parent instructs a child to complete a task without discussion, physicians would dictate the care of patients without knowledge of their patients' preferences. The SUPPORT study of end-of-life care of hospitalized patients, published in 1995, showed that physicians were not well informed about their patients' preferences and that less than half of physicians knew that their critically ill, hospitalized patients preferred to avoid resuscitative measures and that half of the advance directive orders were written within two days of death [3]. Following the publication of this revolutionary study, the necessity for a new approach to patient-physician interaction became apparent. In 2001, the Institute of Medicine stated that "patient-centered care," 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," would become a core goal of the US health care system [4]. In the following years, further studies showed that patient-centered care improved patient satisfaction with physicians, quality of care, and health utilization [5, 6].

As the approach to care changed at the level of individual patient-physician relationships, there was a parallel shift in health care systems and policy. When approaching broader health care systems, the concept and development of co-creation becomes important as first implemented in the commercial world, with its "production" and "services" divisions. Businesses began incorporating individual customer preferences into the production division over half a century ago [7], and the concept of co-creation—the joining of the consumer and producer to jointly influence the development of a product—was developed. Two marketing professors pushed this concept of customer involvement into the service industry in 2008 [8]. Co-creation in the health care system, similar to the concept of patient-centeredness at the level of individual patient-physician relationships, encourages the involvement of the patient in care but at the level of developing new health care policies that are broadly implemented [9]. Patients thus have an opportunity to aid in the development of policies based on their own experiences.

The Relevance of QI Principles in Implementing Co-Creation Projects

Focus on the patient. Incorporation of patient preferences and ideas into the development of health care policies can be challenging in a system that only recently has encouraged a shift away from its traditional paternalistic roots toward patient centeredness. Physicians and other clinicians often feel more knowledgeable and superior to their patients, thereby undermining patients' opinions, as is evident from the remarks of clinician members of the council about the "complexities" and "inefficiencies" of patient involvement in this case. As mentioned earlier, one of the four essential pillars for successful QI projects is the focus on patients [1, 2]. Instilling in and reminding the QI council team members that involvement of patients is an important and founding principle can help further the project. When there is a focus on the patient, understanding the patient's concerns becomes paramount. This focus also allows for acknowledgement of issues, ideas, and shortcomings, such as recognition of the need for patient education, which might not have been previously considered. In this case, Dr. Stevens has an essential role to play in facilitating patient involvement. The patients should be counseled on the importance and advantages of early mobility in fall prevention, and the QI group will need to evaluate the population of patients for which the intervention is relevant.

Focus on being part of a team. Physicians and other medical staff team members can often feel that the inclusion of patients in the involvement of QI projects hinders and slows the progress of the project, creating a tension between efficiency and inclusivity. In these cases, the second of the four QI principles becomes important: the need to focus on being part of a team. It is essential for members of the team to acknowledge that each of the other team members is an asset. Each team member has different knowledge and experience that informs his or her ideas and principles [1]. For example, Dr. Tarib can provide information about the medical physiology behind a fall, Mr. Collins can attest to barriers in patient mobility on the floor, and the patients can relate personal experiences of falling and rehabilitation. Development of an intervention for QI projects is multifaceted and involves multiple disciplines. Taking advantage of individuals' and divisions' unique characteristics in a multidimensional approach will allow the council to view falls from multiple vantage points. It is each individual's responsibility to listen and be open to new ideas [1].

In this case, Dr. Stevens should not capitulate to the demands of the clinician members of the QI team by removing the patient members of the team. Their input is invaluable in the QI process. However, as the team leader, she can hold herself accountable for promoting team efficiency by setting meeting agendas, a clear plan for communication, and a process for decision making. By reducing the tension between efficiency and inclusivity, Dr. Stevens can hope to address the concerns of the clinician members while still incorporating the viewpoints of the patient members of the team.

QI as a system and process. QI is divided into two major components: what is done and how it is done. Process mapping can help evaluate or redesign a current process to meet the specific needs of the health service delivery system [9] by allowing an organization to better understand what and how care is provided and if that care is congruent with evidence-based guidelines. It is imperative that those who implement policies and practices in health care systems be both responsible and accountable to patients who are the recipients of service delivery, which often involves communication, education, and explanation of the details of the service. In the case of Dr. Stevens, accountability would involve integrating the opinions of the patients who would be the recipients of the fall prevention program into the QI process to produce the most effective program possible.

Focus on data. QI strives to allow the care team and the patient to interact productively and efficiently to achieve optimal health outcomes. We measure these outcomes by focusing on data, whether it is quantitative or qualitative [1]. Using standardized performance measures and focusing on existing data, people can identify opportunities for improvement and monitor the improvement over time. Since Dr. Stevens's team members are concerned about time, she can suggest implementing the best co-produced version of the fall prevention program with a clear timeline for evaluating its efficacy and promptly incorporating changes based on feedback from actual patients experiencing the program. This would be another way to engage patients in the development of the fall prevention program by responding to data.

Conclusion

In conclusion, co-production is valuable and necessary for the development of effective quality improvement projects. In this case, Dr. Stevens should not limit patient involvement at the request of the clinician members. Instead, she can refer to the four principles of QI—focus on patients, focus on teamwork, focus on use of data, and understanding QI work as systems and processes [1, 2]—to remind physicians of the purpose of QI programs and to emphasize the need for patient participation in order to truly provide patient-centered care. By keeping in mind these four principles, QI teams can co-produce services that enhance the quality of care provided to patients, utilize patients' knowledge in service delivery, integrate patients' opinions to enhance the quality of the system or process, and finally generate solutions that are more effective and efficient.

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ETHICS CASE

Should Health Care Organizations Use Information Gleaned from Organization-Sponsored Patient Support Groups in Strategic Planning?

Commentary by Priya Nambisan, PhD

Abstract
Online forums and partnerships with patients have several benefits, such as the creation of new products and services. However, as with any such initiatives, there are risks as well as benefits. Through analysis of a case of misinformation being spread through a health care provider-sponsored online support group for patients dealing with obesity, this article outlines best practices and strategies to deploy in such organization-sponsored patient support groups. These strategies would enable organizations and patients to use such forums to the fullest extent while preventing or managing their potential risks as best as possible.

Case

In an effort to help patients become more proactive managers of their own care, the National Star Health Network has asked Dr. Smith, an advocate for how online support groups can help patients, to lead the development of a National Star-sponsored program that would help patients in its network form online support groups, which enable sharing of information, stories, questions, or concerns. It's also hoped that the organization could gain important insights from what patients share in these online forums, such that the organization could develop services that are more responsive to patients' concerns.

Dr. Smith's team has recently initiated an online support group for patients who are obese. She hopes that this online group will not only be a source of empowerment for patients but also help the organization reap the benefit of patients' input in its ongoing strategic planning efforts to improve health outcomes for patients with obesity. When asked why they join the online group, patients state that they hope to support one another and also hope to offer suggestions to the network about how to be more responsive to health needs of obese patients in the community. Participation in the online support group is not anonymous, but participants can use aliases. Participants must check a box stating that they agree to share only information that is "true, to the best of my knowledge."

One participant shares that she lost weight by using a supposedly FDA-approved weight-loss assist device. "To use it," she explains to the group, "You just eat and then drain ingested but still undigested content from your stomach before you absorb the calories." This participant's experience generated a lot of excitement among other participants, so she shared the manufacturer's website for the device. Soon, other participants began to ask their physicians about it.

Dr. Ngwar is an internal medicine physician with National Star Health Network who has numerous patients with obesity who have been asking him about this device over the last few weeks. He calls Dr. Smith to explain his concerns. "Several colleagues and I have been getting pressure from our patients to insert this device in their stomachs. Some of these patients are refusing to try other weight loss methods, claiming that they've learned on the internet that other interventions are pointless. When we ask our patients how they learned about this device, they tell me that it's from the online forum that we sponsor. Is this true?"

Dr. Smith admits that the forum could certainly be a source of misinformation and clarifies that there are currently no clinicians or patient educators staffing the forum to respond to participants who are not well informed or who appear to be exaggerating alleged successes of a particular solution. Dr. Ngwar continues, "We need to do something about this. Patients are threatening to find other physicians willing to insert this device if we don't. I know that sponsoring these patient groups is part of the network's strategic plan to obtain patients' input about the services we offer, but this is just physician-assisted bulimia. I don't know a physician who would recommend this for a patient, and I don't know anyone in health care who endorses the use of this devise. Are we seriously considering offering this to patients?"

Commentary

Offering an online patient forum is perhaps one of the most important patient-centered initiatives a health care organization (HCO) can pursue. Studies indicate that such online patient forums can serve as a powerful vehicle for (a) knowledge creation and utilization [1, 2], (b) disseminating information to the patient community [3], (c) creating new products and services in partnership with patients (i.e., value co-creation) [2], (d) providing empathic support to patients [4], and (e) enhancing the image of the sponsoring organization [5].

As with any other organizational initiative, however, there are also some potential risks. For example, poor management of an online patient forum is likely to lead to patient dissatisfaction and frustration, dissemination of incorrect information and ensuing liability issues, improper patient expectations, and so on. Thus HCOs must carefully manage their online patient forums to maximize the benefits and minimize the associated risks. However, to do so requires developing a deeper understanding of what goes on in such online patient forums. Who are the people participating? Why are they participating? What kind of conversations are going on? And, importantly, how and when do the patients benefit from these conversations in the online forum? This case analysis will put forth strategies to maximize benefits and minimize risks of online patient forums.

Preventing and Managing the Spread of Misinformation through Online Patient Forums

One potential risk associated with online patient forums is for the forum to become a conduit for misinformation, as evidenced in this case study. Misinformation on online forums, blogs, websites, and social networking sites is likely to be a serious threat to patient well-being as well as to the patient-clinician relationship, with much misinformation (e.g., linking vaccinations and autism) being spread through social media sites such as Facebook and Twitter [3, 6]. Although in certain instances, such misinformation sharing could be intentional (e.g., due to paid promotion of specific products), in other instances, it could be unintentional, as patients might truly believe that they are sharing valid information that would be of benefit to others. The latter scenario is particularly true in patient forums where there are discussions of alternative treatments, some clinically proven and some not. Patients who do not have the requisite knowledge to know the difference could innocently share misinformation.

In the National Star Health Network, a patient posts information regarding a supposedly FDA-approved weight loss intervention on an online patient support forum set up by the HCO. Although no clinician or patient educator monitors the forum, it should be noted that misinformation about weight loss shortcuts is available everywhere. Furthermore, one could argue that the patients in the forum who were excited about the device were likely susceptible to misinformation about weight loss shortcuts whether acquired from the forum or another source. However, in this case scenario, the discussion in the forum has clearly extended beyond the online community to Dr. Ngwar's office and his interactions with patients, as some of these patients want this supposedly FDA-approved weight loss device to be inserted in their stomachs. As such, it has become imperative for the National Star Health Network to adopt appropriate measures to minimize the potential negative effects of the sharing of misinformation on the online patient forum without curtailing the free flow of information and the ensuing benefits to patients. Below I suggest some approaches by which health care providers like National Star Health Network and health care professionals like Dr. Ngwar can address this situation at multiple levels and in multiple settings.

At the point of contact with the clinician. Each clinician-patient interaction is an opportunity to discuss and clarify misinformation. However, it is important for health care professionals to be the "guide on the side" rather than the "sage on the stage" [7]. In other words, they should be nonjudgmental and focus on facilitating patient learning through a more participatory model of patient care instead of relying on the traditional paternalistic model [8, 9]. Even educated smart people can fall for misinformation. It is important to allow patients to reach the right decision themselves. Studies have shown, for example, that decision aids to increase patient involvement in decision making improve patients' understanding of the possible benefits and harms of treatment [10, 11]. The goal of patient participation in decision making can also be achieved by asking questions such as "do you think it is the right decision?," "do you know of the side effects or long-term effects of this surgery?," and so on. In the current case scenario, Dr. Ngwar should not only use decision aids but also provide supplemental information (e.g., on the side effects, poor quality of life, and other long-term issues that could potentially arise with this surgery), possibly through an interactive computer game or a visual simulation. One should recognize, however, that many of the patients who are asking their physicians about the device may be tired of trying "healthy options" and thus not be readily persuaded by the evidence. In such situations, it would be more effective if health care professionals could help patients to recognize the factors that are driving them towards potentially bad decisions and enhance their ability to distinguish misinformation from correct information to prevent their making bad decisions in the future. Training for health care professionals would go a long way in helping to realize this objective. Nevertheless, there are strategies, practices, and policies that HCOs such as the National Star Health Network could adopt now to help their clinicians manage misinformation.

At the organizational level. HCOs can adopt clear-cut policies on how to deal with patients who submit misinformation (to their physician or to online forums). Studies indicate that such situations require an effective communication strategy and often the development of a new set of communication skills for health care professionals [12, 13]. It is advisable not to immediately dismiss the information relayed by patients, as patients could put forward potentially useful information [12]. Instead, when seeing patients or monitoring an online forum, it is better to ask for time to collect additional information on a given issue [12] and then promptly get back to patients with information that is relevant and helpful for them to make an informed choice. This approach not only helps the patient to make an informed decision but also demonstrates to the patient that the information he or she provided is taken seriously by the clinician. More generally, validating patients' efforts to seek health information on the internet has been shown to result in improved patient satisfaction and patient-clinician trust [14]. Another approach to dealing with misinformation is to redesign the patient-clinician relationship to suit the organization by choosing one (or a combination) of the following models as a long-term strategy: a professional-centered model, wherein "expert" opinion is relayed to the patient; a patient-centered model, wherein both the health care professional and the patient together evaluate the new information; or a guidance model, wherein the clinician accepts patients' need for new information and seeks out and shares such information with patients in order to guide them [13].

The above strategies will be beneficial in the short-term (such as in helping Dr. Ngwar address his patients' concerns); it is equally important to simultaneously deploy forum-level policies and strategies to address broader issues that arise about the purpose and organization of such online patient support groups.

Effective Models for Using an Online Forum to Its Maximum Potential

An important and broader question posed by National Star Health Network's patient forum in this case concerns how health care organizations can glean useful information for value creation from such organization-sponsored online patient support groups. Online forums provide an excellent venue for HCOs to "listen" to their patients by providing a written text of patient conversations that can be analyzed. Organizations could also take an active approach to gleaning useful information from the forum by partnering with forum members to create new knowledge. Nambisan and Nambisan [2] suggest four models of value co-creation with patients in online forums: the *support-group model*, the *diffusion model*, the *open-source model*, the *diffusion model*, and the *partnership model*. These models are based on two dimensions: the nature of leadership (is the forum organization-led or patient-led?) and the nature of knowledge activity (does it involve new knowledge creation or knowledge sharing?).

Support-group model. The most passive strategy would be one in which the organization takes a completely hands-off approach and leaves patients in the forum to interact with one another in hopes that they will be able to derive some value out of it by sharing information. This approach seems to have informed the National Star Health Network's online forum as described in this case study. Such online support groups have been found to provide empathic support to patients [5] that in turn could lead to positive health outcomes. However, the disadvantages include the potential for patients' sharing inappropriate information or misinformation and the HCO's inability to manage the associated risks. Many HCOs adopt this approach since it calls for very minimal resource commitments on their part [4]. Indeed, support group models have been found to function as a cost-effective auxiliary service that, in the long term, could potentially improve patients' perceptions regarding the organization and its services [4, 5].

Diffusion model. HCOs can also take an active approach to knowledge sharing or diffusion [2]. For example, in the case of the National Star Health Network, the HCO can provide new information to patients and thus keep them up-to-date on recent developments in obesity and associated treatment options or in healthy living. HCOs could provide educational materials (e.g., through its website) to help patients better evaluate information (e.g., related to varied weight loss remedies) they acquire from the online forum or the internet. Importantly, this model also allows the HCO to diffuse information on new health care services through the online forum.

Open-source model. Another relatively passive approach from the clinician's perspective—the open-source model—delegates to patients the generation of new ideas related to improving existing health services that could benefit them as well as the organization. The National Star Health Network's online forum reflects this approach insofar as patients shared information about a new treatment with their physicians. As in this case, the approach can lead to challenging situations in which some ideas might be deemed clinically unsafe or undesirable by the HCO. An appropriate strategy would be for the HCO to filter the ideas and reward those that are deemed most useful or innovative by instituting idea competitions or contests. For example, in this case scenario, Dr. Smith could collect all such patient-contributed ideas from the online forum and present them to an internal team who could then evaluate which of those ideas are worthy of further consideration.

Partnership model. A more active approach is the partnership model, wherein the organization takes the leadership role and specifies very clearly how and for what purpose it wants to partner with patients in creating new knowledge. Examples of such active partnership with patients include clinical trials, in which patients are called on to report side effects of certain treatments or drugs, give feedback on new health care services, and so on [2]. The data obtained from these activities in the online forums could then be analyzed and used for making strategic decisions within the organization regarding treatment options, prescription drugs, or developing new patient services [1].

Conclusion

Overall, these models of value co-creation offer a portfolio of choices or options for HCOs—each with its own advantages and disadvantages—to actively engage with their patients in developing and sharing information about new programs and offerings. Clearly, Dr. Smith and her team could provide feedback on the health-related information that patients bring to the forum or their clinician to address patients' insistence on receiving clinically unproven treatments that they heard about online. However, what is also evident from this case study is the need for the National Star Health Network to adopt a more active model for value co-creation by using the online forum to glean and share valuable information that would eventually benefit the National Star Health Network, its clinicians, and, importantly, its patients.

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THE CODE SAYS

The AMA *Code of Medical Ethics*' Opinions Related to Co-Creation of Health Care Systems

Danielle Hahn Chaet, MSB

"Co-creation" refers to an interactive process in which stakeholders work together toward a mutual end [1]. The health care system in particular is large and complex, however, and this complexity brings with it many stakeholders who might have opposing interests. Because no large-scale health care system, or even clinical institution, can exist without physicians, co-creation of these systems will be discussed in the context of physicians' roles. The *Code of Medical Ethics* has several opinions that provide guidance to physicians striving to collaborate with others to create systems that can efficiently serve multiple stakeholders' interests.

Institutional Settings

Hospital administrators and nonclinical stakeholders may have a different perspective than physicians on what constitutes a "good" or effective institution. They may not have a deep understanding of how logistical issues such as bed allotment can impact care at the bedside. For this reason, physicians who are in leadership positions within their health care institutions should offer their perspectives to other stakeholders on issues that may impact patient care.

Specifically, Opinion 10.8, "Collaborative Care" [2], encourages physicians in leadership roles to advocate on the institutional level "for the resources and support health care teams need to collaborate effectively in providing high-quality care" [2]. Such supports include "education about the principles of effective teamwork" and related skills training [2]. Physicians should also promote "the development and use of institutional policies and procedures … to address constructively conflicts within teams that adversely affect patient care" [2]. In the context of co-creation, the team typically comprises any number of individuals—physicians, nurses, administrators, social workers, and, importantly, patients. In each case, the physician-leader of the co-creative team needs to be the advocate for an environment that promotes strong and effective collaboration between all parties.

Large Health Care Systems

Opinion 11.2.1, "Professionalism in Health Care Systems" [3], speaks to the issues and challenges of co-creation in health care systems on a larger scale. As stated in the opinion,

> Models for financing and organizing the delivery of health care services often aim to promote patient safety and to improve quality and efficiency. However, they can also pose ethical challenges for physicians that could undermine the trust essential to patient-physician relationships [3].

Challenges to co-creation might occur "when payment models and financial incentives … create conflicts of interest among patients, health care organizations, and physicians" [3]. Myriad other barriers to co-creation might arise when relationships are affected by "structures that influence where and by whom care is delivered" (such as health maintenance organizations) or by "tools intended to influence decision making" (such as formularies) [3]. Because of the complexity of health care systems, physicians who are in leadership positions during the creation or reorganization of large health care systems need to ensure that "practices for financing and organizing the delivery of care" are transparent and reflect input from physicians and patients as stakeholders and also to recognize practices that could undermine physician professionalism, such as overreliance on financial incentives [3]. Certain incentives are ethically acceptable as long as they are fair, evidence-based, support high-value care, and mitigate conflicts of interest. Practices for financing and organizing the delivery of care "should be routinely monitored to … identify and address adverse consequences" and to "identify and encourage dissemination of positive outcomes" [3].

The *Code* clearly recognizes the important role that physicians play in the co-creation of various types of health care systems. Physicians have not only a unique understanding of clinical experience at the bedside but also an ethical obligation to treat their patients as of paramount importance. This combination of experience and responsibility allows physicians as co-creators of health care systems to work with other stakeholders to implement systems that promote high-value care.

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MEDICAL EDUCATION

Co-Creating an Expansive Health Care Learning System

Alan Cribb, PhD, John Owens, MA, PhD, and Guddi Singh, MB BChir, MPH

Abstract

How should practices of co-creation be integrated into health professions education? Although co-creation permits a variety of interpretations, we argue that realizing a transformative vision of co-creation—one that invites professionals to genuinely reconsider the purposes, relationships, norms, and priorities of health care systems through new forms of collaborative thought and practice—will require radically rethinking existing approaches to professional education. The meaningful enactment of co-creative roles and practices requires health professionals and students to negotiate competing traditions, pressures, and expectations. We therefore suggest that the development of what we call an "expansive health care learning system" is crucial for supporting learners in meeting the challenges of establishing genuinely co-creative health care systems.

Introduction

Co-creation means bringing together health professionals, patients, providers, and other key stakeholders to jointly address health care problems [1]. If this is to be feasible, then clinicians (and other stakeholders) need to be prepared for co-creation, which would entail ambitious changes to health professions education. That, at least, is what we intend to argue in this article, and, in so doing, we also hope to indicate the breadth and depth of the relevant ambition for medical education. We define what is needed as an "expansive health care learning system" that challenges traditional conceptions of, and boundaries between, teachers and learners and theoretical and practical expertise [2].

All professional education, in every sector, is intended to transcend boundaries—for example, between the classroom and the workplace, theory and practice [3], the official and hidden curriculum, and so on. Classrooms and other formal educational settings are valuable for providing spaces to explore practices and to question prevailing norms, but unless whatever is learned in them can be translated into the wider world, learning is likely to have a short half-life [4]. We can easily imagine a medical student, let's call her Jenny, learning about co-creation in medical school and then cycling to work at a hospital and discovering that her desire to co-create—for example, to involve patients in service redesign—is not shared by her colleagues or, more fundamentally, by the norms of her workplace. Can—and how might—the pieces of her and our learning environments be better matched up? In this article, we review the opportunities for and challenges to building co-creation into the medical school classroom, the hidden curricula of both medical schools and workplaces, and the broader health care system.

Teaching and Enacting Co-Creation in Medical Schools

The opportunities for relevant learning in medical school are substantial. Jenny could learn about the principles and experience putting them into practice [5, 6]. For example, the curriculum might stress the importance of shared decision making between health professionals and patients [7]. This focus could include some reflection on both the ethical and instrumental rationale for shared decision making—that it treats patients with respect, harnesses multiple stakeholders' perspectives and expertise, and is responsive to patient values. Co-creation could therefore be presented as central to ensuring that health care is effective and valuable in terms that matter to health professionals, patients, and other stakeholders [8]. There could also be some emphasis on the *practices* of shared decision making, including perhaps the communication challenges of working with patients who might resist taking an active role in decision making. Possibilities for addressing these challenges could include helping patients access and use decision aids and, through that process, students learning from nursing colleagues or physician assistants who are already experienced in, and employed in, roles that support such practices.

More fundamentally still, many aspects of the medical school curriculum could themselves be co-created such that the school seeks to practice what it preaches. This level of reform, which involves organizational change to model and foster collaboration, is more demanding than simply revising the content of a curriculum, but could be undertaken in a number of ways: through patient and public involvement in the co-creation and enactment of curricula, pedagogies, and assessments [9]; through interprofessional education in which members of different occupational groups learn to work together and to understand the complementarities (as well as some of the tensions) in doing so [10]; and through peer-assisted learning in which students, acting either as teachers or as teacher-course developers, work with staff to foster a learning culture and to support one another [11]. Such examples of collaboration or partnership can still involve someone taking a leadership role but typically entail less hierarchical relationships, especially between clinicians and patients [12]. These more fundamental kinds of reform are challenging to bring about, but they have the potential to create deeper forms of learning—that is, deep-seated values and attitudes—because they allow students like Jenny to practice and not just hear about co-creation.

For the individual learner, such depth is crucial if learning is to be more than merely a cognitive appreciation of co-creation. The whole person, including his or her dispositional and affective makeup, needs to be influenced by the practice of collaboration for learning to be sustained and realizable through ongoing habits of mind and action [13]. But achieving this kind of embedded learning is dependent upon a significant degree of support and reinforcement from medical school cultures and practices. The medical school itself—and not just isolated individuals—both embodies and reproduces values and habits, which is why there is—rightly—so much emphasis on the power of the hidden curriculum in medical education [14]. Everyone knows that there is a difference between "talking the talk" and "walking the walk." The official curriculum might radiate gentle messages of partnership, teamwork, relationship-centred care, and so on, accompanied by talk of reduced hierarchies of power and knowledge, but these messages can easily be cancelled out by a hidden curriculum that reinforces traditional hierarchical arrangements within medicine. In other words, not just individual students like Jenny, but their educators and the norms of learning institutions, need to change "root and branch" if co-creation is to be something more than an aspiration or, at best, a very partial and patchy development.

Barriers to Co-Creation in Health Professions Education

The challenges produced by what we have said thus far are substantial. It is not only that the changes required to embed co-creation in medical education are extensive and that there are many motivational and practical obstacles to overcome, but also that these obstacles cannot simply be seen as a product of inertia, blind resistance, or conservatism. Rather, there are fundamentally important questions to be asked about the merits (and drawbacks) of the old and the new—questions about how best to integrate co-creation into meaningful and viable forms of education and what is best about long-standing traditions of professional expertise and authority [15]. There are fundamental debates about the trade-offs between potentially conflicting roles and values, such as encouraging participation from patients versus "off-loading" responsibilities onto patients or professional versus patient priorities [16].

Such debates need to be consciously addressed not only at an organizational level but also by individual students such as Jenny and by experienced professionals as they move between contexts and cases [17]. Indeed, learning to co-create can be seen as making substantial new demands on all professionals. In structures and cultures defined by co-creation, the core activities of health professionals demand expertise in managing new kinds of relationships and in value questions as well as clinical questions. That is, health professionals will typically need to be accomplished in forming and sustaining relationships under conditions of partnership and skilled at facilitation and guidance while simultaneously being ready to question their own assumptions. This inevitably creates a series of complex balancing acts and value dilemmas. For Jenny to feel reasonably confident about engaging in co-creation she will need to have thought about, and tried to practice, navigating such debates and related dilemmas.

However, as we have indicated, an even greater set of challenges arises because properly embedding co-creation in health care professional learning would require analogous structural and cultural reform that extends beyond medical schools across the whole health care system. The most influential currents of the hidden curriculum are to be found outside of medical schools because they are embedded in the cultural norms and institutional constraints of workplace settings. Unless these wider cultures and structures are reformed, then Jenny will effectively be forced to unlearn the principles and practices of co-creation that she acquired in medical school in order to fit in with the realities of her hospital work.

Having acknowledged the challenges of co-creation here, we will not dwell on them. There is always time, on another day, for caution and qualification, but in what remains of this article we prefer to focus on what we see as the substantial implications of co-creation. We describe these as "substantial" not only because they involve the root-and-branch changes we have already discussed but also because they have relevance across the whole health system.

Expanding Learning

There are reasons to be both ambitious and optimistic about building the values and strategies of co-creation into health care education. Major transitions are taking place in health systems and in many respects these will necessitate new approaches to learning. Something of this dynamic is captured in the already established idea of a *learning health care system* [18, 19], a label that suggests both the breadth and depth we have in mind. It usefully conveys the idea that the conditions for learning should be in place everywhere and always and that this learning should require us to rethink and rework some of our core assumptions and categories. The emphasis to date has been upon the remarkable potential of digital data. The advent of electronic health records, along with the capacity for ever-expanding, real-time monitoring (including self-monitoring) and data analytics, provides the system with the capability to learn from and for every single patient [20]. Yet we would suggest that this version of a learning health care system, while certainly valuable and quite far-reaching, is too limited in scope. Realizing the possibilities of digital learning will itself require new forms of co-creation with patients because access to and use of digital data depends upon new collaborative relationships among individuals, groups, and health systems. Relatedly, the realization of a health care learning system involves rethinking traditional assumptions about confidentiality and data usage being centred on one-on-one clinician-patient relationships and about the distinction between individualized care and public health more generally [2].

For these reasons we would argue that embedding co-creation in health systems requires an expansive learning health care system. The limitation of the more circumscribed lens is that the learning involved will simply be about the optimal utilization of data (important though that is). But the challenge of co-creation is more extensive: it is, as we have noted, about the potential control of the health agenda; who defines purposes, relationship norms and priorities; and how these things are negotiated and settled [17]. The learning needed for, and fostered by, a co-creating health system, including medical education, is expansive in multiple senses: in addition to being a pervasive possibility, it would position all actors as both teachers and learners; it would operate with a holistic and fluid conception of expertise (incorporating, for example, expertise in relationships and values); and it would be oriented not just to cognition but to all aspects of persons—their practices, dispositions, and emotions.

This account of how to transform health professions education for co-creation is obviously more of an overarching vision than a practical strategy. In reality, the resistance from both medical school and workplace hidden curricula, as noted above, would be considerable and would, to some extent, inhibit the potential of co-creation indicated here. Nonetheless, there is something to be said for reviewing ideals before getting bogged down with the practicalities. If Jenny is to learn how to successfully manage co-creation in her immediate encounters, then system leaders need to be ready to contemplate what co-creation might mean at a system level, the conditions that might support that endeavour, and the myriad kinds of learning required.

Conclusion

We have argued that co-creation can have far-reaching implications for medical education and the health system more generally. If the next generation of clinicians and other health care actors are to be properly prepared, medical schools and workplaces must not only teach but also practice collaboration and counter some of the traditional norms embedded in hidden curricula. We suggest that ambitious and expansive thinking is needed if this is to happen.

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STATE OF THE ART AND SCIENCE

How Should Organizations Promote Equitable Distribution of Benefits from Technological Innovation in Health Care?

Satish Nambisan, PhD, and Priya Nambisan, PhD

Abstract

Technological innovations typically benefit those who have good access to and an understanding of the underlying technologies. As such, technology-centered health care innovations are likely to preferentially benefit users of privileged socioeconomic backgrounds. Which policies and strategies should health care organizations adopt to promote equitable distribution of the benefits from technological innovations? In this essay, we draw on two important concepts—*co-creation* (the joint creation of value by multiple parties such as a company and its customers) and *digitalization* (the application of new digital technologies and the ensuing changes in sociotechnical structures and relationships)—and propose a set of policies and strategies that health care organizations could adopt to ensure that benefits from technological innovations are more equitably distributed among all target populations, including resource-poor communities and individuals.

Introduction

In the past decade or so, the health care industry has seen a rapid infusion of a wide range of digital technologies and associated innovations—from enterprise-level systems such as electronic medical records (EMRs), e-prescribing systems, and patient portals, to personal health systems such as personal health records and personal health mobile apps. There is emerging consensus among researchers and policymakers that these health information technologies do have a positive impact on many different health care outcomes including efficiency and effectiveness of care, access to care, patient involvement in care, patient satisfaction, and preventive care [1-4].

At the same time, benefits from such new technologies and associated solutions are in general likely to accrue to those who have access to and good understanding of those technologies. Early evidence does indicate that the benefits from health care technological innovations preferentially accrue to users from privileged socioeconomic backgrounds and those with higher levels of e-health literacy (i.e., the ability to use digital technologies to find relevant health information and apply the knowledge gained to improve health or address a health issue) [5-7]. If this evidence is correct, then what policies and strategies should health care organizations (HCOs) adopt to ensure that the benefits from health care technological innovations are more equitably distributed among all target populations, including resource-poor communities and individuals?

In this essay, we address this question by drawing on two important concepts from research on innovation management and digital technologies: *co-creation* and *digitalization*. We briefly describe these two concepts and then identify three foundational themes that emerge from their joint consideration. Based on these themes, we propose a set of policies and strategies that would allow HCOs to play a more proactive role in ensuring that the benefits from technological innovations are more equitably distributed among all target populations.

Co-Creation and Digitalization

Co-creation. Co-creation relates to the joint creation of value by multiple parties—for example, by a company and its customers [8]. It implies a shift from merely *consulting* with a set of external stakeholders (e.g., users or customers) to actively *collaborating* with them in identifying problems and developing solutions. With the emergence of the internet and other digital technologies (e.g., mobile computing), the scope and depth of such customer involvement in innovation has changed radically [9]. It has become possible for customers to engage in all the phases of innovation—from ideation, to design, to development, to implementation, to support [9]—and to contribute to a greater level of innovativeness, faster turnaround, and enhanced perceptions of a product's quality and satisfaction with a firm [10-12]. For example, BMW, the German automaker, set up a co-creation lab (a virtual environment with online design tools for customers to develop their innovative ideas) that led to the generation of over 400 design ideas related to interior design, urban mobility, telematics, and driver assistance systems, many of which were incorporated by the company in its future cars [13]. Similarly, in the public sector, such initiatives have ranged from Boston's Citizens Connect initiative (which allows citizens to identify and report civic problems using a mobile app) to the Danish government's Climate Consortium Denmark (a series of workshops to bring together citizens, businesses, and experts in co-creating new strategies to combat climate change while driving new business growth) [14]. Numerous other examples of such consumer-led co-creation exist in the private sector [10] as well as in the public sector (citizen co-creation) [14, 15].

The co-creation perspective has also been applied to the health care context and implies the promise and potential of embracing health care consumers (i.e., patients) as partners in innovation and value creation [16-18]. Such co-creation approaches could enable HCOs to develop more innovative value-added services at lower costs and improve patients' experiences with those new offerings [16]. For example, when launching a new weight loss drug, GlaxoSmithKline (GSK) invited 400 overweight men and women to use the drug and to share their drug-related experiences by participating in its online community. The new knowledge generated from those consumer interactions was instrumental in the design of the educational materials that accompanied the drug as well as in the creation of templates for individualized or customized treatment plans (which was crucial for the success of this drug). Importantly, such knowledge also enabled consumers to manage the learning curve associated with the drug, thereby enhancing consumer satisfaction with the new treatment and creating positive perceptions regarding the quality of the new product [16].

Digitalization. Digitalization relates to the "*sociotechnical process* of applying digitizing techniques to broader social and institutional contexts" [19]. The concept of digitalization goes beyond digitization (i.e., digital conversion), emphasizing the changes in sociotechnical structures and relationships triggered by the infusion of new digital technologies and applications [20, 21]. Such changes might include new business models, new intermediaries (e.g., data analytics portals, crowdsourcing platforms), and new collectives (e.g., online communities). And, in some cases, these changes in sociotechnical structures might lead to new innovations, reflecting the inherent generativity of digital technologies [21]. For example, data portals and other intermediaries established to collect and analyze data from personal health and wellness devices (such as Apple Watch and Fitbit®) have in turn given rise to new health care offerings. For example, Apple HealthKit helps integrate personal health data with enterprise-level electronic health records and allows for diagnosis. Thus, the reconfiguring of the underlying sociotechnical relationships between new (digital) products and services and users (or consumers) calls for organizations to better understand how their health care offerings fit into and refashion the everyday life of consumers. More broadly, the digitalization perspective implies the need for HCOs to look beyond the immediate offering or technology artifact (e.g., patient portal) and consider how the technology redefines consumers' relationships and exchanges with peer consumers as well as the HCO (and other institutions) to better understand the adoption, use, and value derived from such offerings.

Foundational Themes: Educate, Engage, and Evolve

Health care organizations deploy new technologies and solutions to ensure efficient and effective health care delivery to *all* of their customers and to promote the well-being of all individuals and communities. However, as noted previously, consumers who have better access to and understanding of the new technologies and who are well positioned in the emergent sociotechnical structures are likely to benefit more from the health care innovations. And certain sections of the consumer population—for example, individuals in resource-poor communities, seniors, or the aged with limited education, and consumers in regions with limited access to the internet and other foundational digital technologies—are likely to be at risk of not benefiting from these valuable innovations [6, 7]. It thus becomes incumbent on HCOs to adopt proactive strategies to ensure equity in the distribution of benefits from their technology-centered health care innovations.

Importantly, such equitable distribution of benefits would not only serve to fulfill HCOs' mission of enhancing individual and societal health and well-being but also advance their business goals by ensuring a larger customer base for new offerings.

The joint consideration of co-creation and digitalization implies three important themes—*educate, engage, evolve*—that together could inform HCO strategies and policies.

- *Educate*. Knowledge about health care problems and solutions is heterogeneous, dynamic, and distributed among different stakeholders (including different sets of patients). For example, patients from a specific background (say, those with low e-health literacy) might possess unique knowledge about their needs (say, the need for additional help in interpreting online health data and test results) and how potential solutions might (or might not) fit the everyday context in which they would be used. To enhance innovation success, knowledge must flow both ways: HCOs need to educate consumers on the innovation *and* consumers need to educate HCOs on the context of their everyday usage of the innovation.
- *Evolve*. New (digital) technology-based innovations bring about changes in sociotechnical structures, and these changes in turn modify the ways in which new technologies are developed, perceived, or used by health care organizations and their consumers. For example, new wearable devices such as Fitbit and the personal health data they provide have not only led to the creation of data portals and other intermediaries but also forced HCOs to reevaluate how physicians should use such consumer-owned data in diagnosis and treatment [22, 23]. Such gradual co-evolution of the innovation and its associated sociotechnical structures could continue over the lifetime of the innovation. Thus, HCOs need to be cognizant of these dynamics and adapt their strategies and practices appropriately.
- *Engage*. Health care consumers' involvement in innovation allows them to be active players—rather than bystanders—in the reshaping of the sociotechnical structures associated with the infusion and adoption of new digital technologies and innovations. For example, with the emergence of wearable devices, consumers have created several online forums to identify and discuss key usage-related issues and problems and, importantly, to develop and offer free solutions to some of those problems (e.g., apps to export data to specific software platforms or to integrate data with EMR data, and so on). Such active consumer engagement in various phases of innovation, in turn, would enable HCOs to be more proactive about building and supporting the appropriate infrastructure to enhance innovation success.

Strategy and Policy Guidelines for Health Care Organizations

Based on the above foundational themes, we suggest a set of policies, strategies, and practices for HCOs to ensure that the benefits from innovations do flow to all the target populations, including resource-poor communities and individuals.

Establish a portfolio of mechanisms to educate (and learn from) diverse sets of health care consumers. HCOs should establish varied mechanisms to enable peer-driven consumer education about the innovation and its associated benefits. Studies indicate that such peer-based initiatives could help assuage consumers' issues and concerns related to an innovation, as they perceive peer consumers as "one of us" and hence their inputs to be more trustworthy [10, 24]. More importantly, such initiatives allow peers to share critical insights on the changes they made in their particular usage context to enhance the benefits they derive from the innovation [10, 24, 25]. Given the relatively high penetration of mobile technologies and social media among all sets of consumers—for example, a 2017 Pew Research Center report indicates a sharp uptick in both smartphone ownership and social media usage among both lower-income Americans and those aged 50 and older [26]—an effective way would be to utilize social media platforms and online communities to serve as the venue for knowledge sharing and peer education. Forums that cater to specific target populations (e.g., based on socioeconomic background) or focus on specific health care concerns (e.g., obesity) would likely experience higher levels of participation and knowledge sharing [16]. HCOs might also need to provide additional innovation-related information (e.g., on how consumers might use an innovation with other complementary innovations to maximize benefits) and set up special incentive systems (e.g., community recognition or more tangible rewards such as discounts on HCO offerings for consumers who offer help and guidance to their peers in online forums) to promote continued consumer interactions [10].

Establish a portfolio of mechanisms to engage with diverse sets of health care consumers in innovation. HCOs should establish diverse online and offline mechanisms to engage with different target populations of health care consumers in developing and implementing technology-centered innovations. Such mechanisms include web-based forums for consumers to report problems with existing HCO offerings, e-petitions that allow consumers to express their collective opinions on desired services, innovation jams or online brainstorming sessions that engage with a broad set of consumers on specific health-related issues, and participatory design workshops that allow for community-level consensus on the design of solutions to specific problems [14]. These mechanisms can be customized to target specific sets of consumers and their engagement in specific phases of the innovation process. For example, consider an HCO trying to enhance the diffusion of its patient portal among customers with limited e-health literacy. The HCO could conduct a participatory design workshop at the local community center (that would make the process accessible to all) and focus on developing a deeper understanding of the challenges that those customers face in using the patient portal. Importantly, the workshop would also serve as the venue for community members and the HCO to come together in designing new processes (and solutions) that would enhance the innovation's fit with the community's local context. Thus, the broader objective of these mechanisms is to embrace the consumer community as an equal partner in identifying problems and in solving them and, in the process, ensuring a better fit between the innovation and the consumers' own context.

Establish mechanisms to enable the co-evolution of the innovation and its associated social or institutional context. HCOs should establish mechanisms that would help consumers "visualize" and interpret the potential interdependencies between an innovation and their own immediate social or institutional context. Given the advances in digital technologies, it has become easier and more cost effective to build "virtual experience centers" that allow potential users to "experience" new services or technology-based innovations before they purchase or adopt them [27, 28]. For example, a gamification approach has been used to educate nurses about the workflow changes needed for EHR adoption [29]. Such virtual experiences would be particularly useful to consumers with limited technology resources or e-health literacy to answer questions such as: "How would this innovation fit with the everyday context in which I would use it?" "What specific benefits would I get?" "What changes would I need to make to derive them?" The broader objective should be to enhance the "trialability" of new technology-based solutions that in turn would enable potential users to better understand and adapt the innovation by making appropriate changes in their usage context (e.g., workflow changes to accompany EHR adoption).

Adopt an ecosystem perspective when developing and implementing health care innovations. HCOs and their innovations do not exist in a vacuum; rather, they coexist with a community of interacting and interdependent entities. An *ecosystem perspective* acknowledges this fact and offers an organizing structure for an ensemble of actors (e.g., patients, health care agencies, community-based nonprofits) to come together and co-create service offerings. It calls for: (a) building and sustaining a community of (consumer) innovators and promoting a shared perspective on their environment (a "shared worldview"), and (b) defining and implementing an "architecture of participation" that offers a clear set of rules and guidelines for knowledge sharing and collaborative innovation [14].

Adapt the HCO organization to engage with health care consumers. HCOs need to adapt their internal structures and processes to effectively link the "internal" (e.g., employees, business processes) with the "external" (patients and their communities). It ensures that the insights about problems (or solutions) gained from interactions with patients are acted upon by the HCO and result in viable new services, policies, or offerings. Such adaptations of internal structures and processes might include dedicated staff positions (e.g., to connect specific patient communities with internal innovation teams) and new processes (e.g., to evaluate patient ideas and suggestions and enhance transparency related to innovation activities). If such changes are not made to internal structures and processes to adapt them for patient engagement, external ideas are likely to experience a "slow death," and, more importantly, lack of results are likely to discourage patients from future engagement [14].

Position consumer co-creation as part of a broader HCO initiative. HCOs need to view the consumer co-creation approach as part of their broader patient-centered initiatives. Doing so would allow HCOs to support and evaluate such initiatives, not as stand-alone activities, but as important ingredients in their overall approach to fulfilling the core agenda related to patient care—for example, providing equality in health care delivery or enhancing patient self-care. Organizations that embed consumer co-creation activities within their overall customer relationship management framework would be able to find synergies with other customer-centered initiatives (for example, with initiatives to enhance patient experience and satisfaction) and, importantly, make such efforts more meaningful to both the internal participants (HCO employees) as well as the external participants (patients) [10].

Conclusion

New digital technology-based health care innovations portend considerable benefits and value to health care consumers across the spectrum. At the same time, if left to chance, those benefits are unlikely to reach certain segments of the consumer population, particularly consumers in resource-poor regions and communities. In this essay, we proposed that strategies and policies that place central importance on consumers and on the sociotechnical changes unleashed by new digital technologies could help HCOs play a more proactive role in ensuring that the benefits from technological innovations are more equitably distributed among all target populations.

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Why Aren't Our Digital Solutions Working for Everyone?

Brian Van Winkle, MBA, Neil Carpenter, MBA, and Mauro Moscucci, MD, MBA

Abstract

The article explores a digital injustice that is occurring across the country: that digital solutions intended to increase health care access and quality often neglect those that need them most. It further shows that when it comes to digital innovation, health care professionals and technology companies rarely have any incentives to focus on underserved populations. Nevertheless, we argue that the technologies that are leaving these communities behind are the same ones that can best support them. The key is in leveraging these technologies with: (a) design features that accommodate various levels of technological proficiency (e-literacy), (b) tech-enabled community health workers and navigators who can function as liaisons between patients and clinicians, and (c) analytics and customer relationship management tools that enable health care professionals and support networks to provide the right interventions to the right patients. Finally, we argue that community health care workers will need to be incentivized to play a larger role in building and adopting innovations targeting the underserved.

Narrative: Heart Failure and the Failure of Remote Monitoring

Jeremy lives in a small subsidized housing development with his mother and three sisters. At 52, he struggles with heart failure with reduced ejection fraction. This year alone, he has visited the emergency department four separate times. Luckily, a nearby hospital has recently been focusing on reducing readmission rates for heart failure in response to increasing incentives related to value-based care. The hospital is exploring promising technologies that might help Jeremy: inexpensive remote monitoring devices that are connected wirelessly to a broadband router through Bluetooth®. The solutions require Jeremy to use a scale and arm blood pressure cuff to record daily metrics that are sent wirelessly to his cardiologist. The idea is that, if clinicians can monitor Jeremy on a real-time basis, they can evaluate his health to see if he is deteriorating or stable. They can then use this information to proactively schedule an appointment or to make a medication adjustment. The solution, like many designed to prevent costly emergency visits or readmissions postdischarge, is considered to be integral in bending the cost curve and improving health. The problem is that none of these solutions are working. Jeremy is only becoming sicker and more frustrated. He lives in a home where wireless internet connection is spotty. The connection is not dependable enough to download search engines, let alone to routinely send signals from his arm cuff to his clinician. Jeremy also repeatedly forgets to take his medication. In short, our "promising" digital technologies are not helping Jeremy at all.

Barriers to Digital Health Solutions

Digital health solutions are increasingly being touted as the key to solving the two great health care problems of our time—cost and access [1]. While the quantitative impact of these digital solutions is still yet to be determined [2], their potential for driving the next generation of care is indisputable [3, 4]. But, as with other historical transformations, the solutions and associated shifts risk leaving certain groups or individuals behind [5, 6]. The transition to digital health and the opportunities it provides are causing a widening gap between those who are "connected"—that is, those who can access *and* use technology services and tools that rely on internet or wireless connectivity—and those who are not. We highlight three barriers to leveraging digital solutions to address underserved patients like Jeremy:

1. *Poor internet connectivity and low e-literacy*. Many disadvantaged communities have poor broadband access, part of a growing digital injustice that has been well documented [7-9]. These same communities suffer from associated low technological proficiency, or low e-literacy, that renders most emerging digital health solutions ineffective [10].
2. *Those who design technological solutions tend to overlook those most in need*. Those who design technological solutions are almost exclusively well-educated and wealthy [11]. Meanwhile, high-cost and high-need patients tend to be older, more diverse, and less educated [12].
3. *Limited incentives to focus on innovations targeting low-income patients*. Many physician practices have financial incentives to explore new technologies as a way to differentiate themselves from competitors [13], but they are often focused on attracting commercially insured patients. Meanwhile, safety net health care professionals rarely have the means or incentives to explore innovative technologies [14].

These issues pose ethical questions for health professionals. What responsibilities do facilities and their clinicians have to explore low-tech innovations targeting underserved communities? Are health professionals violating ethical guardrails by introducing technologies in communities of the primarily well-to-do? What obligation does the profession have to create an entrepreneurial environment for solutions to be designed for patients who actually need them? These questions have historically been answered (or left unanswered) according to health professionals' own ethical inclinations. But as value-based incentives grow around at-risk patients, clinicians will increasingly look for strategies and tactics on how to better manage patients like Jeremy.

What Can Be Done to Rectify Digital Injustice?

The technologies that are leaving disadvantaged communities behind are the same technologies that can best support them. The key is in leveraging them with (a) design features that accommodate various e-literacy levels; (b) tech-enabled community health workers, who can function as liaisons between patients and professionals; and (c) analytics that enable health professionals to push the right technologies to the right patients. Finally, the industry will need to (d) incentivize health care professionals to play a larger role in building and adopting innovations targeting the underserved. Before any of these changes can happen, however, communities will need to be provided with internet access and electronic health (e-health) education programs. Each of these innovations can solve at least one recognized problem (see table 1).

Table 1. Mapping tech-related solutions to issues

Solution	Issue		
	Poor connectivity or low e-literacy	Tech not designed for those in need	Limited physician incentives
Expand coverage and provide e-health education	√		
Design tech for underserved communities	√	√	
Use tech-enabled community workers	√	√	
Connect patients with the right resources	√	√	
Develop programs to incentivize clinicians		√	√

Expand internet coverage and support e-health literacy training programs. Investments in broadband to optimize the use of digital health resources are beginning to target digital inclusion issues [15, 16]. These investments are steps in the right direction, but access will need to be paired with education and support programs to be effective. In her paper on novel approaches to technology adoption, Amy Sheon and colleagues lay out several well-supported suggestions for internet access programs, free digital skills training, and commercial partnerships to equip, educate, and connect low-income residents [8]. They call for engaging community health workers to screen health system patients for digital skills and connectivity. They also refer them to networks of community organizations that developed under the $4B Broadband Technology Opportunities Program to access low-cost internet and free digital skills training [16]. The community health workers would then provide specific training in using digital health tools [5]. In Jeremy's case, instead of relying on the clinician to educate Jeremy on the technology, the hospital could have partnered with local education programs to set up and support the use of digital technologies in Jeremy's home. Jeremy could have been enrolled in free digital skills training to help him monitor his condition with low-tech equipment. Sheon and colleagues' recommendations constitute a critical starting block on which our subsequent suggestions build.

Design technologies for underserved patients. Few health applications are adapted for patients with low e-literacy rates [17]. To be effective, technologies need to be designed for people with different levels of digital competency and needs for assistance in using these tools. Rather than potentially ill-equipped health care professionals being tasked with training their patients, specialists with expertise in digital skill acquisition could help ensure patients' proficiency with digital solutions [5]. Caretakers should be able to leverage various types of remote monitoring technologies for the same disease, understanding that each person responds to, and uses, technology very differently. The Network of Digital Evidence in Health (NODE Health), a nonprofit consortium of health care systems (including the authors' organization, LifeBridge Health) that serves "to promote evidence based digital medicine" [18], is beginning to adopt a tool and simple questionnaire to understand the "digital fingerprint" of patients. The tool, RxUniverse, developed by Sinai App Lab, aggregates the most effective evidence-based apps, care plans, and health education materials available onto a single platform, which then allows clinicians to prescribe *simple* digital medicine solutions directly to patients based on the assessment of the patient's digital skills and digital engagement [19]. Jeremy, for example, could have been screened by a community health worker to understand the type of internet or wireless coverage he had or the types of phone reminders that best suit his digital abilities. If he had a cell phone, text messages could have been sent to his phone reminding him of medication guidelines, and, if he had a smartphone, he could have been provided free access to a home monitoring system via cellular networks rather than broadband. With this in mind, questions like "What kind of applications do you use and how often?" could become one of the most important questions a nurse practitioner can ask in the transition of care.

Integrate tech-enabled community health workers into community programs. Rather than inject technologies into communities, we would be better served by providing community health workers with digital tools that can respond to or supplement low-tech monitoring or simple messaging devices. For example, Jeremy could have been provided with community-based home visits, which have been shown to enhance compliance with medications and to reduce readmissions of patients with chronic diseases [20]. The routine home visit by a community health worker with a mobile monitor could have facilitated a virtual visit with a remote clinician. Responses to the Ebola crisis may be one of the best examples of empowering digitally-equipped health workers in remote, disconnected areas. During the crisis, several low-tech solutions were developed to provide health workers in Guinea with basic surveillance and communication tools, supported by low-tech, flip-phone telehealth solutions. These solutions were a far cry from the more advanced user experience platforms on today's smartphones, but in resource-constrained environments, they were utterly transformational [21].

Connect patients with the right resources. In some ways, the ultimate promise of digital technology is not the ability to deliver or manage care remotely but the ability to better customize the entire interaction between the patient and the health care system. Such customization could facilitate leaps forward in our ability to improve health, to enhance the patient experience, and to reduce cost [22, 23]. Table 2 gives examples for each of these goals and how analytics can help patients like Jeremy.

Table 2. Managing disadvantaged patients now and in the future

Managing low e-literacy patients	
The present	The future
Improving health	
A patient with chronic heart failure (CHF) might see any cardiology specialist, if the patient sees any at all	CHF patients are matched with a clinician based on patient specifics (history, level of acuity, other needs) and a providing team's experience and past performance with CHF patients
Patient experience	
With limited preference information, systems do not know how, when, and where to reach patients in the most effective manner	Based on both preset and learned preferences, patients indicate their preferences for alerts and notifications
Reducing cost per capita	
Health systems routinely route high-need patients to high-touch, high-cost programmatic inventions based on their clinical condition	Generic clinical populations are divided into more specific, actionable subpopulations and matched with intervention programs based on their likelihood of success for patients with similar characteristics

Incentivize community providers to play a greater role in community innovations. Until there are more opportunities for underserved patients to play a greater role in the design of digital technologies, community health facilities and their clinicians will have to represent their patients and ensure the integration of digital solutions into their care. To facilitate this endeavor, medical associations could consider a fellowship fund for physicians to work with technology firms to focus exclusively on at-risk communities. Patients from underserved communities could collaborate with these firms and physicians in order to ensure that the newly designed digital technology meets the population's needs [24]. Medical associations could also collaborate with organizations like NODE Health and payers, social services, tech startups, venture capitalists, and safety net health care professionals to develop and share a common business case for accelerating innovative technologies targeting the underserved.

Conclusion

Digital health tools have the potential to change how we provide care [25]. To fully realize this potential, communities will need to have connectivity, digital educational programs, and tech-enabled community health facilities and professionals to support them. Programs will also need to be created to incentivize health professionals and tech companies to focus on disadvantaged communities. Until this happens, those left on the wrong side of the digital divide will experience widening health disparities.

> *Four months after Jeremy was provided with the keys to solving the health crisis, he made one last visit to the emergency department, having collapsed in his apartment after a sudden cardiac arrest. For the four months preceding this event, Jeremy was equipped with what many would have considered to be the latest digital technologies needed to manage his disease, but, sadly, he was unable to manage the technologies. Despite all the promising digital innovations emerging in health care these days, Jeremy died the old-fashioned way.*

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POLICY FORUM

Using Principles of Co-Production to Improve Patient Care and Enhance Value

Puja Turakhia, MS, and Brandon Combs, MD

Abstract

Unlike goods, which are concrete and easily quantified, services are intangible processes that are produced and consumed concurrently. Health care is a service that can encourage optimal health outcomes only through meaningful, collaborative partnerships between patients and clinicians. Co-production of health services can be used as a means to rethink how health care is delivered not only in the context of face-to-face encounters in which the benefits of working together are obvious, but also in designing systems that can improve patient care and enhance value.

Introduction

The concept of co-production was introduced in the 1960s as the United States shifted from an industrial economy focused on the production of goods (e.g., manufacturing) to a service economy (e.g., retail and banking) in which consumers and producers worked together to create value. Co-production occurs when consumers are engaged in the development of a service or product, thereby helping to ensure quality and enhance value [1]. Value co-production occurs in particular when consumers are able to personalize their experience while using an organization's service and in return undertake specific tasks needed by the organization [2]. This process requires active collaboration by consumers and producers to create value [3]. A familiar example of a good being transformed into a dynamic, co-produced service is the manner in which ride-hailing services such as Uber or Lyft have used personal automobiles and mobile devices to revolutionize the way people travel. Users of such ride-hailing services can travel more quickly and efficiently while the companies themselves generate significant revenue.

Health care systems are sometimes viewed as a producer of goods, which in this paper we delimit to health outcomes. It is readily apparent, however, that health outcomes are not simply created by health care professionals or hospitals but are contingent upon the complex interplay between clinicians, patients, and health care systems. For example, reduction in colon cancer mortality via a screening program requires health systems willing to provide financial and logistical support, knowledgeable clinicians versed in the risks and benefits of available screening modalities, and engaged patients empowered to convey their preferences, with the result that a shared decision can be agreed upon and implemented. The building blocks of value co-production include transparency, dialogue, access to collaborative patient-clinician relationships, and an understanding of the balance of benefits and harms of proposed health interventions [4]. Co-production of value and the collaborative approach it requires can be used as a means to rethink how health care is delivered not only in the context of face-to-face encounters where the benefits of a collaborative approach are clear, but also in designing systems that can improve care and enhance value. Here we explore the concept of value co-production applied to health care systems and the shift in medical culture necessary to implement it. We also highlight the importance of measuring the success of co-production through health care metrics.

The Benefits of Co-Producing Value

Co-producing value in health care starts from the fact that patients and clinicians exist within a larger system that can promote or impede progress toward optimal care. Batalden et al. have proposed a theoretical framework for co-production wherein "patients and professionals interact as participants within a healthcare system in society" [5]. At the center of this framework are clinicians and patients; clinicians solicit patients' priorities and values in order that patients can partake in clinical decisions whenever possible.

The existence of meaningful partnerships wherein patients and clinicians work together is ideal for several reasons. Engaging patients in their own care can promote increased confidence and willingness to take control of their health, which ultimately can lead to healthier behaviors and improved outcomes. For example, among patients with diabetes followed over six months, those who scored higher on a measure of confidence in managing health-related tasks were more likely to perform foot checks, exercise regularly, and receive recommended eye examinations [6]. In addition, more engaged patients consistently report more positive experiences including higher-quality interactions with their clinicians and fewer problems coordinating their care [7]. In a systematic review of quality improvement literature assessing patients' engagement in their own care—for example, through patient forums and patient representation at practice planning meetings—specific changes attributed to enhanced engagement included improvements in access to care (e.g., extended clinic hours) and simplified appointment procedures [8]. It is evident that engaging patients in their own care could have benefits that extend beyond the individual patient. Health systems could also benefit by revising existing protocols on the basis of patient feedback. For example, improving access via online scheduling applications could allow health systems to utilize existing staff more efficiently.

A collaborative approach to care that recognizes clinicians as experts on medical science and patients as experts on their own values and preferences can be cultivated in several ways. For example, advisory committees that include clinicians and patients can be assembled to discuss patient concerns in the community, such as increased flexibility in hospital visiting hours. Such opportunities for stakeholders to come together in order to brainstorm and implement new policies facilitate open communication and can create space to forge trusting relationships [9]. Creating this space allows both clinicians and patients to address their needs, and ultimately both parties can benefit from the implemented change. By actively engaging patients in every step of the clinical process, we can consider new methods to improve care.

When involving patients in planning and implementation of new health care policies, it is important that patients from diverse communities and backgrounds be represented. Just as the National Institutes of Health has now mandated that research should be done with patients from diverse populations [10], health care organizations should follow this principle within their institutions. Patients of all backgrounds should partake in co-producing health care policies and changing services for their communities. Ensuring that a representative sample of patient and clinician voices is heard is essential in creating an open, collaborative culture [10]. Finding common ground among both parties can help create the foundation from which to work, with both patients and clinicians involved in co-producing strategic planning within health care organizations.

Changing the Culture of Health Care Delivery

It might not be easy to change the culture of health care delivery to better promote collaboration between patients and clinicians, but such a shift is essential. Viewing patients not as “users and choosers” but as “makers and shapers” allows for planning and implementing new policies that can potentially lead to better health outcomes and patient experiences [11]. In addition, viewing clinicians as providers of services rather than mere goods is a needed conceptual shift in traditional medical culture. Educating clinicians and patients on the merits of co-production is one way to get started. Patient advocacy organizations and insurers could encourage patients to be more involved with their care, reminding them that their perspective matters and is integral in developing individualized plans of care. Patients coming prepared to clinic appointments to discuss key concerns and goals for the visit, and thus becoming more active participants in their care, can ensure that important issues are prioritized accordingly and managed efficiently. Although all clinicians intuitively know the importance of listening to patients, this fundamental detail can be forgotten in the often hectic pace of patient care. To promote the central role that listening plays not only in accurate diagnosis but also in matching health interventions to the unique goals and preferences of patients, professional medical societies could launch awareness campaigns with their members and society at large akin to what has taken place with the Choosing Wisely® Initiative and the high-value care initiative of the American College of Physicians [12, 13].

Through the lens of co-production, we can also rethink traditional models of care. As an example, for common low-risk conditions such as upper respiratory infections or acute low-back pain, patients could interact asynchronously with online, scripted templates that could then be reviewed and acted upon by clinical staff [14]. Such arrangements could reduce demand for face-to-face visits, thus increasing access for patients who need them most, such as those requiring complex symptom management or end-of-life care. Improving efficiency with the assistance of health information technologies could also lead to reductions in cost, particularly for health systems that are less reliant on traditional fee-for-service payment models.

Good health outcomes also depend on factors outside the traditional clinical setting where opportunities exist to change existing culture. Community-based roundtable discussions with patients could uncover new opportunities for co-production as health care systems aim to be more lean and patient-centered. Organizations that encourage patients to discuss preferences for their own care with family, friends, and health care professionals can help tailor interventions to individual patients. For example, the Baby Boomers for Balanced Health Care project in Minnesota encourages and empowers community members to discuss matters that are important to them—including overuse of health services—with their physicians and helps them engage in conversations about end-of-life preferences [15]. Grassroots organizations comprising a broad range of stakeholders, such as the Right Care Alliance, can help reimagine patient-centered care through advocacy efforts aimed at promoting evidence-based care that is affordable, equitable, and tailored to individual patients [16].

Measuring Success of Co-Production Initiatives

Patient surveys and quality metrics can be important tools in persuading stakeholders that ongoing co-production efforts are worthwhile [17]. Monitoring the impact of co-production and nourishing sustainable co-production initiatives, however, will require persistence and creativity.

Patient surveys could ask about perceptions of "being listened to" and clinicians could be incentivized to emphasize this important skill. Clinician incentives could include financial remuneration on the basis of patient surveys that address how well they listened and attended to the patient's needs or dedicated training for clinicians supported by health systems. Patient focus groups with frontline clinicians could also be employed by health systems to uncover barriers to high-value care and opportunities for meaningful quality improvement activities. Quality metrics could focus more explicitly on evidence-driven interventions demonstrated to improve patient-oriented outcomes such as aspirin use in patients with cerebrovascular disease or statin use after myocardial infarction [18]. Metrics could also be used to assess the overuse of services when harms are likely to outweigh benefits, such as Pap smears after age 65 and overly aggressive diabetes and blood pressure control in elderly patients [19]. When clinicians and patients value the metrics by which quality is being assessed, buy-in and satisfaction are likely to be enhanced. Since the benefits of reducing the frequency of certain health services might not be intuitive, clinicians should communicate to patients how avoiding low-value interventions can reduce both downstream physical or emotional harms and out-of-pocket health-related expenditures. In this way, patients are likely to have more confidence that the care they ultimately receive is value added.

Other health related metrics—such as reductions in out-of-pocket expenditures for patients, better patient understanding of disease and treatment processes, improved access to clinic appointments, and greater satisfaction of clinicians and patients—can be developed and used to assess the effects of co-production efforts. Evidence has shown, for example, that patient-centered management in the primary care setting can reduce subspecialty referrals and diagnostic tests, thus decreasing financial and opportunity costs for the patient while improving access at the system level for those who need subspecialty consultation the most [20, 21]. Although more evidence is needed regarding the effects of co-production on patient satisfaction and costs of care over time, creating a structure that allows and encourages patients to be active participants is an important step toward optimal care.

Conclusion

Although the concept of co-production is not new, applying its basic principles to health system redesign is an exciting opportunity to examine and implement new ways to improve care. In order for co-productive processes to thrive, patients and health care professionals must be looked at differently. Patients must be viewed less as consumers and more as contributing partners in their care. Health care professionals should be recognized for what they are: as providers of services that can be shaped and improved by ongoing feedback from stakeholders and that can ultimately lead to optimal outcomes rather than as providers of goods that are the outcomes themselves. By creating new opportunities for clinicians and patients to work together and by providing incentives for clinicians, patients, systems, and payers, meaningful collaboration in system redesign can result in improved health outcomes and proceed in a truly patient-centered manner.

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MEDICINE AND SOCIETY

What Are the Professional, Political, and Ethical Challenges of Co-Creating Health Care Systems?

Guddi Singh, MB BChir, MPH, John Owens, MA, PhD, and Alan Cribb, PhD

Abstract

Co-creation is seen by many as a means of meeting the multiple challenges facing contemporary health care systems by involving institutions, professionals, patients, and stakeholders in new roles, relationships, and collaborative practices. While co-creation has the potential to positively transform health care systems, it generates a number of political and ethical challenges that should not be overlooked. We suggest that those involved in envisioning and implementing co-creation initiatives pay close attention to significant questions of equity, power, and justice and to the fundamental challenge of securing a common vision of the aims of and agendas for health care systems. While such initiatives present significant opportunities for improvement, they need to be viewed in light of their accompanying professional, political, and ethical challenges.

Introduction

Worldwide there is a growing awareness of the need to adapt health care systems to meet the challenges of the twenty-first century. The reasons for this need are many but include shifting trends in demographics and illness, epidemiological knowledge of the social determinants of health, the radical possibilities of new technologies, and rapidly increasing health care costs as well as relatively long-standing concerns about the need to respect and support the autonomy of patients [1, 2].

One response to these challenges has been calls for the co-creation of health care systems. Co-creation can take a number of different forms, but at heart it represents bringing together key stakeholders to jointly address problems [3]. In medicine, health professionals, patients, providers, and other stakeholders can be involved in co-creation initiatives including achieving professional-patient concordance through shared decision making, personalization of health services, patient self-management or self-care, and interprofessional or interagency collaboration (e.g., among physicians, nurses, dieticians, podiatrists, and a variety of allied health professionals in caring for patients with diabetes) [4]. Co-creation in medicine typically seeks to extend the role of patients or service users in clinical settings and beyond by encouraging their participation in care processes or service design [4]. It can enable service users to exercise voice and choice and to take up new roles and responsibilities. For instance, in the context of the UK National Health Service, patients with chronic conditions are encouraged to assume "self-management" roles that involve taking responsibility for decision making, administering self-care, and even managing a personal health care budget [5]. Co-creation can also entail broad structural changes, such as partnerships that span clinical or institutional boundaries [3], including those in which health professionals of different stripes are brought together to work with public sector professionals or community stakeholders.

Although co-creation presents opportunities to develop more responsive, integrated, and outward-looking health care systems [6], realizing co-creation in practice means confronting significant professional, political, and ethical challenges. In this paper, we seek to promote critical reflection about some of these challenges. We argue that for co-creation to be successful, these challenges must be recognized, by clinicians in particular, and then negotiated as best as possible.

Common Ground in Diverse Contexts?

We begin by questioning what (for some at least) might be a central assumption of co-creation: that those involved in co-creating health care processes, service designs, or systems will be able to find common ground upon which to base an agenda. The idea that a consensus on the ends and means of health care is self-evident or can be straightforwardly established is problematic for several reasons.

Values in health care are contested [7]. Those involved in health care might have different ideas about what matters most and why. For instance, community stakeholders might seek greater accessibility and equity; patients might value greater safety and convenience; health professionals might want higher quality care, greater patient satisfaction, and fair remuneration; policymakers might prioritize efficiency. Given the diversity of values at stake, co-creation cannot be understood in simple catchall terms, (e.g., as simply about optimizing health outcomes). Moreover, inevitable resource limitations and potentially competing values make it difficult to pursue all potential values at once. In reality, bringing people together to achieve shared goals may prove difficult, as evidenced by patient nonadherence to medical recommendations undermining high-value care [7] or by cases in which patients and clinicians disagree about means and ends [8]. Reaching, managing, and maintaining some convergence of purposes and values is therefore a key challenge for co-creating health systems.

Conceptions and possibilities of co-creation also depend upon context. In addition to the specific clinical circumstances of each situation, local factors—particularly political, economic, and sociocultural circumstances—help determine possibilities for co-creation. The extent to which patients are willing and able to play an active role in their care as “experts” or consumers may differ across institutional and national contexts, as may their abilities, attitudes, and conceptions of entitlements and bargaining power [9]. Equally, the attitudes and behaviors of health professionals and other stakeholders may be influenced by the prevailing norms and expectations that govern the space in which they operate, as well as by the wider legal, political, and economic circumstances that shape their particular roles and responsibilities.

Thus what matters most for co-creative health systems should be decided with reference to local views and circumstances rather than abstract or universal principles. With this in mind, co-creation should rightly involve bringing local citizens, patients, health care practitioners, policymakers, and other stakeholders together to discuss the dilemmas inherent to processes of agenda setting in health care. Throughout these discussions, sensitivity to divergent interests and perspectives will be key to building a consensus.

Challenges of Changing Professional Roles

Having examined the difficulties involved in finding a consensus upon which to base co-creation initiatives, we now consider some of the broader challenges associated with implementing co-creation in practice.

A key element of co-creative health systems is their potential to usher in new roles for professionals, patients, and stakeholders, creating fresh possibilities for identity and relationships [10]. Co-creation could therefore transform the professional roles of clinicians by challenging them to continuously attend to, and negotiate, diverse interests and perspectives within and beyond the clinical terrain [8, 9]. For example, when patients present with complex physical and mental comorbidities that are caused and sustained by adverse economic and social conditions, effective care might require a combination of medical, psychiatric, and social contributions. Such cases might require a more “socially conscious” model of medical professionalism—a model that is, for example, sensitive to the intersections of class, race, gender, and culture and how these factors are bound up with people’s health experiences and opportunities [11]. No doubt some health professionals are “socially literate”; however, cultivating high levels of “social consciousness” is generally not well supported within medical training or professional practice and development [12, 13]. If co-creation is to become the norm, then a broadening of both initial medical education and ongoing professional development will be needed.

Role change may present welcome opportunities but it also raises important ethical questions. For instance, professionals will need to reconsider how far their practice is oriented towards the patient in front of them or the wider public. If patients are encouraged to act as consumers of medical services, deciding who should take the lead in clinical decisions could be a tricky business, especially in cases of serious disagreement [8]. When would a patient-led consultation relegate medical professionals' status to mere facilitators of patients' choices [14]? On the other hand, should socially conscious medical professionals be more ready to consider the interests of the wider population of co-creators? Such questions highlight the significant potential that co-creation has for changing the prevailing norms and dynamics that currently govern clinical or policy decision making. And, to take a further example, role change raises urgent questions about who should be held responsible for co-created decisions. With patients and stakeholders being encouraged to take on additional responsibilities and accountabilities [15], it remains to be seen how far they will be ready, willing, and able to respond [9, 16].

Challenging Hierarchies of Power in Medicine

Behind concerns about role changes are questions about the potential redistribution of power in co-creative health care systems. For good or ill, power hierarchies operate between professionals, patients and stakeholders, and also within these groups. While co-creation has the potential to positively disrupt hierarchies and asymmetries between and within groups that have been viewed as unwanted and oppressive, unless issues of power are explicitly addressed, co-creation could operate to reinforce existing power relations [17]. This is a particular risk when the language of co-production or co-creation is used in relatively superficial ways and disguises a situation in which one group has substantially more say than another, just as the rhetoric of compliance seems to endorse uncritical prescribing practices [18].

An effective redistribution of power will depend upon the extent to which issues of power are openly discussed by those involved in the co-creative process. The continuous possibility of disagreement and friction requires a culture of open and authentic deliberation wherein roles, relationships, and procedures are discussed by all those involved, who, as we have mentioned above, come together to find a degree of convergence about the values and agendas of care. A critical dilemma this raises for medical professionals is how to manage the ceding of control. Clinicians could see co-creation either as a threat or as an opportunity to replace paternalism with mutual trust [19]—the long sought-after goal of the patient-centered movement. The potential for clinicians to act as guides for, and partners with, patients navigating the economic and political agendas of co-creative heath systems could thereby expand—rather than constrict—their professional influence in very profound ways.

Challenges of Equity and Justice

If health care systems are to become genuinely co-creative, attention must be paid to who has opportunities to participate—in both decision making and actions—and on what terms [20]. By introducing new roles, partnerships, and collaborative models, co-creation offers the opportunity to proactively engage patients and other stakeholders who typically have been marginalized within clinical settings. Questions must be asked about whose voices are heard and whose are not, and which views are considered important and which are not. Negotiating the processes of participation and representation will therefore be a key challenge for those seeking to foster co-creative systems. Approaches to system evaluation will be needed that balance the diverse views and interests of multiple agents and groups, to avoid, for example, situations in which customer satisfaction or efficiency eclipses competing concerns for public health or patient safety. Finding a balance might be difficult, especially when some interests are deemed to be of marginal value or in cases in which disagreement is founded on entrenched political or cultural opposition (as may be the case with the provision of abortion services or the extension of health care services to the uninsured). Here, consideration of the ways and extent to which co-creative health systems can be made to support health equity and social justice will be fundamental to their success. For example, leaders could establish deliberative mechanisms by which patients, health professionals, and stakeholders can discuss and review the norms and principles that will govern and sustain co-creative health systems.

Co-Creation: Transforming Health Care?

Co-creation provides an opportunity to take stock and consider the possibilities for transforming health care systems by bringing together citizens, professionals, organizations, and institutions to renegotiate key values and relationships. While the opportunities for change are significant, ambitions for co-creation must be assessed in light of what is practically and politically achievable and mindful of ethical dilemmas. However, for better or worse, co-creation offers the chance for clinicians to reconsider the purposes of medicine and for patients and other stakeholders to have their voices heard and respected. Co-creation therefore provides a platform for understanding medicine in far broader terms than at present, enabling the social dimensions of health and the long-standing inequalities and inadequacies of health care systems to be illuminated and transformed. This is certainly not a risk-free endeavor. If it is to be a success, co-creation will require the rebalancing and renegotiation of multiple roles and relationships and the promotion of more complex forms of coordination and collaboration. The risks and challenges are significant, but so, too, are the potential rewards.

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HISTORY OF MEDICINE

How Co-Creation Helped Address Hierarchy, Overwhelmed Patients, and Conflicts of Interest in Health Care Quality and Safety

Sigal Israilov and Hyung J. Cho, MD

Abstract

Co-creation is health professionals' and systems' development of health care together with patients and families. Such collaborations yield an exchange of values, ideas, and priorities that can individualize care for each patient. Co-creation has been discussed interchangeably with co-production and shared decision making; this article explores co-creation through the lens of quality improvement. Although there are barriers to co-creation including physician autonomy, patient overwhelm, and conflicts of interest, co-creation has been shown to promote patient engagement, peer learning, and improved outcomes. Further research is needed in co-creation for systems improvement.

The History of Co-Creation

A recent development in health care, co-creation has roots in the fields of management and public policy [1]. At its core, co-creation refers to a process of gathering input from various stakeholders with the common goal of producing a service or product [2]. Since multiple parties contribute to a collective effort in co-creation, the resulting service or product is theoretically of value for all involved [3]. In such a system, creation shifts from being a top-down to a negotiated process [4].

The notion of co-creation was first formulated by Elinor Ostrom more than three decades ago [5]. In her case studies of public officials in Kenya and Brazil, Ostrom described the high level of public input that was gathered before decisions were made about infrastructure and education [6]. The first step in the design of new sanitation systems, for example, was setting up neighborhood meetings. This allowed citizens to express their specific needs and be informed about the effects of construction in their neighborhood [6]. Since this groundbreaking work was published, the applications of co-creation have progressed substantially. Now interchangeable with co-production, co-creation provides an incentive to mobilize resources, broadly construed, for service planning [4]. In other words, the combination of different points of view is considered a resource in and of itself, especially when the partnership utilizes marginalized viewpoints as previously unexplored community resources [7].

Co-creation in health care involves partnerships between health professionals and patients. The designation of patients as active participants in the health care team is not new, however. In 2001, the Institute of Medicine identified patient-centered care as one of six fundamental pillars of high-quality care in the US health care system [8]. While this designation acknowledges the importance of patients in the care setting, we argue that patient involvement is equally crucial in the administrative setting. Co-creation allows patient-centered care through the integration of the patient in the development of the system: in co-design of services, co-delivery of services, co-commissioning of services, and co-assessment of services [9]. Health professionals' and patients' partnerships in all these phases of development can transform goals of care, health care delivery, and communication systems [2]. In this article, we will focus on co-creation at the systems-level: quality improvement integrating the patient voice in co-design and co-delivery of services.

Challenges and Limitations

Some challenges exist in incorporating co-creation into quality improvement. Traditionally, medicine has been paternalistic and hierarchical, with an emphasis on physician autonomy [10]. The hierarchical nature of health care settings can create an imbalance of power in meetings, placing patients and patient advocates at a disadvantage [11]. Other challenges include added complexity in process, low patient health literacy, and conflicts of interest [12]. Yet if these obstacles are overcome, the rewards of co-creation can be immense—improved patient health literacy, patient empowerment, and the development of quality improvement initiatives that cater to all stakeholders [11].

Hierarchy. Realignment from physician-centric to patient-centric models of care remains a barrier to the implementation of co-creation, including for purposes of quality and safety [13]. Historically, administrators and clinicians have operated with autonomy and fair efficiency in changing health care. Input is quickly gathered among local quality administrators and medical experts, and plans are expeditiously implemented to improve care [14]. Changes are made in rapid improvement cycles by reviewing pertinent amounts of data to determine efficacy [15]. Involving patients and patient advocates in these steps can often seem time consuming and inefficient within a traditional workflow [16]. Attaining consensus within a committee can be challenging, and the addition of a member who is not part of the medical staff can add complexity, particularly if he or she is a patient or patient advocate [17].

Patient overwhelm. While physicians' desire to maintain their autonomy can be a major barrier to co-creation, patients' relative lack of medical knowledge can be a barrier as well, as the sheer complexity and volume of information overwhelms their decision-making capacity [18]. This informational overload hinders informed consent and the patient's ability to engage in shared decision making with the physician. Often, when faced with such medical complexity, patients relinquish their decision-making authority to the physician. Similarly, in quality improvement, patient advocates may defer judgment to physicians or administrators. For example, patient advocates might be asked to be involved in the development of a patient-centered pathway for syncope admissions. While patient advocates may feel comfortable discussing items such as the lack of communication about telemetry monitoring, which involves the use of noisy alarms [19], they might not feel comfortable contributing to the discussion of the appropriateness and timing of this test due to a lack of medical training. Nevertheless, their input may be invaluable in creating a patient-centered model. One potential product of such a collaboration is a patient-friendly education pamphlet regarding the appropriateness and benefits of telemetry, similar to what has been recommended for pain management [20]. This pamphlet would reduce patients' frustration and possibly testing refusals while making monitoring more efficient. Another example of patient advocates collaborating in quality control might be a root cause analysis following a medical error event. A root cause analysis involves a formal, multidisciplinary event review that identifies the root cause of the error and offers suggestions for systems improvement to prevent the same error from occurring in the future [21]. In delicate situations of this kind, which sometimes involve blame of (and defensive behavior from) certain staff members, an anonymous voting process such as the modified Delphi method might be helpful for patient advocates by allowing them an equal vote in the assessment and plan [22].

Conflicts of interest. Another possible barrier to incorporating multiple stakeholders in the quality improvement process is conflicts of interest. For example, a quality improvement workgroup on developing an efficient myocardial infarction pathway might involve physicians, nurses, quality administrators, and patient advocates. It is crucial for patient advocate members to disclose any financial conflicts of interest ahead of the process, as a patient advocate who has received payments from a company that makes drug-eluting stents might bias the committee in favor of this particular treatment over a bare metal stent or a noninvasive treatment. Indeed, in one national survey, 67 percent of patient advocacy organizations reported receiving industry funding and 82 percent indicated that conflicts of interest are at least moderately relevant to the work they are involved in. As more patient advocates become involved in health care—in clinical trials, guidelines, and quality and safety initiatives [23]—the greater will be the need for standard disclosure practices in patient advocacy organizations. Since physicians are obligated by medical societies and hospitals to disclose any conflicts of interest on a regular basis, the same should to be expected from patient advocacy organizations [24].

Benefits of Co-Creation in Health Care

While challenges to co-creation exist, the evidence for its benefits is increasing. Patients who have been involved in the quality improvement process exhibit increased levels of empowerment and health literacy [11]. For example, in a qualitative study, patients who had received training in interprofessional collaboration and care partnerships at the University of Montreal identified themselves as valuable resources to the health care team due to their experiential knowledge, unique perspective, and tangible impact on the care of fellow patients. These patients also reported an improved understanding of the health care system and its nuances as well as of their own health and ways to maintain it [25].

In addition, co-creation has been shown to increase the efficiency of the quality improvement process. A report by the Institute for Healthcare Improvement demonstrated that involving patients in root cause analyses following adverse events allows risk management professionals to optimize the interventions their organization needs [26]. For example, in an analysis of a system failure involving a cardiac catheterization procedure that led to an unexpected complication, the subjective viewpoint of a patient who has gone through a similar experience is invaluable and allows clinicians and administrators to modify the environment. A patient's perspective can also help guide changes to improve the informed-consent process and communication with the patient and family when complications unexpectedly arise. Such a perspective is a resource [4], and co-creation at the level of feedback and redesign is crucial.

The benefits of co-creation in quality improvement can be maximized by following a standardized approach to patient engagement. Experience-based co-design (EBCD) provides physicians with a structured approach to co-creating improvement initiatives with patients and family members by training stakeholders how to start a quality improvement project, how to establish a core group, how to collect staff and patient experiences, how to set up a co-design event, and how to celebrate successes [27, 28]. With proper implementation, co-creation models have the potential to improve quality and patient safety. For example, within a decade of beginning system-wide improvement efforts that included establishing patient-family advisory councils, Vidant Health saw an 85 percent reduction in serious safety events and a 62 percent reduction in hospital-acquired infections [29].

Conclusion

Striving towards co-creation in health care is a worthwhile cause. It balances power in the quality improvement process while facilitating peer learning and patient engagement. Although the road to implementation of co-creation is fraught with challenges such as physician autonomy, patient overwhelm, and potential conflicts of interest, co-creation can lead to a system that engages all stakeholders in the improvement of care (see table 1). Already there are standardized plans for engaging patients and families in quality improvement processes [13]. Health care professionals' and systems' co-creation of health care with patients and patient advocates—from the single patient visit to the improvement of the health care system—promise to realign health care priorities in the near future.

Table 1. Challenges and benefits of co-creation

Challenges	**Benefits**
Physician autonomy	Patient engagement
Patient knowledge, overwhelm	Peer support and learning
Conflicts of interest	Improved quality and safety outcomes

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IMAGES OF HEALING AND LEARNING

Healing Hands

Image and caption by David Bryan Lackey, MS

Abstract

For the last seven years, my bride of 45 years has been working very hard to recover from a series of heart problems and two strokes. In 2015, after hundreds of therapies following her 2012 stroke, we were fortunate enough to find a therapist who understood the importance of compassion and empathy in clinical situations. Within a few months, my wife's physical, cognitive, mental, and emotional condition improved profoundly. As a photographer and author, I had been documenting her survival, recovery, and flourishing, and I was fortunate enough to recognize a moment of beauty and captured a single image that has since become my wife's inspiration for living. It is entitled "Healing Hands."

Figure 1. *Healing Hands*. Photo: David Bryan Lackey.

Caption

Art and healing: the beauty and power of human touch in images connects clinicians and patients through empathy and compassion, providing hope and inspiration.

David Bryan Lackey, MS, is a freelance photographer in Atlanta, where he provides portraits of healing to patients suffering from strokes, brain injuries, and devastating injuries in collaboration with his wife. He is a graduate of the Georgia Institute of Technology, where he formerly was an adjunct instructor in the College of Design's School of City and Regional Planning.

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