HISTORY OF MEDICINE

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

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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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