COMMENTARY

A science of collaborative learning health systems

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Abstract

Introduction: Improving the U.S. healthcare system and health outcomes is one of the most pressing public health challenges of our time. Previously described Collaborative Learning Health Systems (CLHSs) are a promising approach to outcomes improvement. In order to fully realize this promise, a deeper understanding of this phenomenon is necessary.

Methods: We drew on our experience over the past decade with CLHSs as well as qualitative literature review to answer three questions: What kind of phenomena are CLHSs? and what is an appropriate scientific approach? How might we frame CLHSs conceptually? What are potential mechanisms of action?

Results: CLHSs are complex adaptive systems in which all stakeholders are able to collaborate, at scale, to create and share resources to satisfy a variety of needs. This is accomplished by providing infrastructure and services that enable stakeholders to act on their inherent motivations. This framing has implications for both research and practice.

Conclusion: Articulating this framework and potential mechanisms of action should facilitate research to test and refine hypotheses as well as guide practice to develop and optimize this promising approach to improving healthcare systems.

KEYWORDS

collaborative learning health systems, science of learning health systems, systems science, theoretical framework

1 | INTRODUCTION

To achieve optimal outcomes, the healthcare system must deliver the right care to the right person at the right time, every time. This is fundamentally a problem of coordination—of getting the right information and interventions to the right people at the right time and place. Solving the coordination problem is the motivation behind personalized medicine, shared decision-making, the chronic care model, and reducing medical errors. Nevertheless, it is evident that solving this problem is difficult, due partly to the large variety of needs and array of potential interventions. No standardization by central decision makers can be expected to allocate the right treatment for each person. Nor is it likely that each professional would know, based only on their own experience, what intervention will be best for every patient in their care. To solve the coordination problem requires organizing the health system in such a way that every person can access resources for acting in ways that improve outcomes, contribute to learning what works best, and share that knowledge seamlessly.

The National Academies of Science, Engineering, and Medicine has described a Learning Healthcare System[1] in which clinical care, science, informatics, incentives, and culture are aligned for continuous improvement, innovation, and research; new knowledge is captured as a by-product of care, and evidence is applied reliably and is seamlessly embedded in the delivery process. This is a promising concept for solving the problem of coordination, but until recently, examples of Learning Healthcare Systems were rare.

We and colleagues have described Collaborative Learning Health Systems (CLHSs), termed Learning Networks,[2] that use a network organizational architecture to facilitate collaboration at scale in order to improve health outcomes. We have described the CLHS framework and methods[2] and the processes used to replicate these and have shown that CLHSs improve outcomes across multiple diseases and conditions and across participating sites with diverse contexts.[3-5] More recently, we have recently described a formal methodology for assessing network maturity.[6] As of Spring of 2021, we know of 11 CLHSs[7] (Learning Networks), encompassing almost 700 teams across almost 300 healthcare organizations in 43 States and Washington, D.C., and five countries. Given that CLHSs have been replicated, within pediatrics, across chronic conditions (eg, Reference 4), inpatient safety,[8-11] preterm birth,[3] and community health,[12] it is appropriate to consider these as a class.

We consider CLHSs to be a subset of LHSs, rather than distinct from LHSs. Camarinha-Matos and Afsarmanesh[13] have distinguished between networking (communicating and exchanging information for mutual benefit), coordination (the act of working together harmoniously), cooperation (not only exchanging and acting on information but also sharing resources for achieving aligned or shared goals) on the one hand and collaboration (a process in which entities share information, resources, and responsibilities to jointly plan, implement, and evaluate a program of activities aimed at achieving shared, aligned goals), on the other. While learning—a major goal of any LHS—can occur as the result of networking, coordination, and/or cooperation alone, CLHSs achieve rapid learning at scale through collaboration as detailed below.

Therefore, although collaboration is assumed to be present to some degree in all LHSs, the reason for highlighting this particular subset as *Collaborative* LHSs is to highlight the role of collaboration and the organizational approach to facilitate collaboration at scale to solve the coordination problem. Hierarchical and other organizations often do not achieve collaboration at scale due to their structure and limited interconnectivity, which tend to support a small number of line-specific functions rather than shared goals and alignment of purpose across the organization. Networks, due to their distributed, highly connected nature, achieve and sustain cooperation and collaboration broadly.[14-16] That is, CLHSs use a network organizational form to facilitate the production and sharing of resources so that all stakeholders (patients and families, clinicians, researchers) can collaborate toward solving the coordination problem.

CLHSs hold great promise, given their impact, as one pathway to improving outcomes through the vision of the Learning Health System. To fully realize the promise of CLHSs, however, we need a deeper understanding of them. Here, we seek to explain—not advocate—as a way to increase understanding of CLHSs. What kind of phenomena are CLHSs and what is an appropriate scientific approach? How might we frame CLHSs conceptually? What are potential mechanisms of action? In this commentary, we suggest answers to these questions, with the goal of helping researchers and practitioners better understand and improve CLHSs, including Learning Networks. Our approach to answering these questions is based on our own and colleagues' experiences, as well as qualitative literature review to synthesize a range of scholarship relevant to CLHSs. We incorporate sources from a variety of fields including complexity, organizational dynamics, political science, evolutionary biology, behavioral economics, sociology, innovation, and system design. We use a simplified example to ground our approach and then consider each question above in turn.

1.1 | Simplified example

Our example uses hypothetical people, composites based on ethnographic research.[17] We build from the perspective of Orleans, a 12-year-old girl newly diagnosed with Crohn's disease. In addition to whatever personal, social, or physiological resources she has, she also has a variety of needs in the face of this diagnosis. Her medical needs include, among others, accurate diagnosis, selecting an appropriate treatment or treatments, and evaluating their effectiveness. She also has needs relating to how to navigate the healthcare system, her life beyond her illness and symptoms, and making sense of her new status as a person with a chronic illness. Corbin and Strauss[18] refer to these domains as "illness work," "everyday life work," and "biographical work," respectively. Moreover, these needs will change over the course of her illness as both she and her condition change.[19] Orleans and her family need resources such as optimal treatment (eg, medicine, appropriate nutrition), information about how and when to call the doctor in between clinical appointments, accommodations at school such as unrestricted restroom access, and support around body image, managing a colostomy, or how to navigate conversations with friends about the disease and its implications. Dr. Roan, Orleans' gastroenterologist has a full panel of patients, and, while she has access to continuing education and Medline, the "gold standard" randomized controlled trial evidence available to her describes the average effect of a single treatment on a highly selected group of patients. How should she counsel Orleans and her family on the best treatment to choose, not to mention Orleans' nonmedical needs?

Orleans is one patient and Dr. Roan is one clinician. Expanding this example across many patients and many clinicians, one can imagine a huge variety of needs. Correspondingly, one can imagine a reservoir of resources, comprised of information, knowledge, and know-how (IKK), potentially available to meet those needs. Bianca, for example, has just graduated from college. Diagnosed with Crohn's disease at 11 years of age, she has learned to cope with the condition, sees herself as an expert patient, and wants to make a difference for others with the disease. Mitch Kapour, a researcher, has developed a system for patients to track the effects of treatments such as the ones Dr. Roan and Orleans are considering. And Veronica Mars, a nurse, has used Dr. Kapour's system to help patients and clinicians learn together about which treatments might work best for an individual patient. Bianca, Dr. Kapour, and Nurse Mars live and practice in different healthcare organizations in cities other than Orleans', and, though they may have similar motivations and shared goals, they do not

collaborate or even know each other. They are three of potentially (hundreds of) thousands of people willing and able to contribute resources to satisfy the needs of people like Orleans and Dr. Roan's. But unless there is a system—like a CLHS—that enables them to act on their motivations to create and share these resources and that makes it easy for people like Orleans to get what is needed when it is needed (WINWIN), the match between resources and needs—and the effect on Orleans' health and well-being—is only potential. CLHSs can be thought of as complex systems that facilitate collaboration toward best care and outcomes. Below, we unpack this statement to answer the questions posed above.

1.2 | CLHSs as complex systems

We view healthcare as a system[20]—a set of related processes that work together to achieve an outcome (as attributed to W.E. Demming). This has several implications, the most important of which are that the people in the healthcare system are enabled and constrained in their efforts and activities by the system itself and that improving outcomes will require us to change the system not just the people in the system. Further, we see healthcare as a complex system,[21,22] more akin to an organism or a society than to a machine. Complex systems are ubiquitous in biological, physical, and social systems. Cells, organs, human bodies, organizations, societies, ecosystems, stock markets, and climate have been described as complex systems.

Complex systems share several characteristics and understanding these sheds light on how we might think about CLHSs. Complex systems are self-organizing; the parts (in healthcare, the patients, clinicians, administrators, technology) interact and react to one another and eventually form stable patterns. Further, it is the pattern of interactions among the parts that is important in understanding the effects of the system; if Orleans and Dr. Roan never meet, if their interaction is not collaborative, or if Orleans cannot fill her prescriptions, it is less likely Orleans will receive—or act on—an appropriate treatment. Complex systems are nonlinear, with implications for change strategies. Thus, interventions applied to the system—incentivizing Dr. Roan to

increase patient satisfaction scores, for example—are unlikely to have the predicted effect. Fourth, complex systems often contain complex sub-systems (hospitals contain wards and clinics, which contain people, some of whom have something amiss with one or more of their organs, and so on), and these systems interact with and interpenetrate one another. Finally, some complex systems—like the healthcare system—have humans in them. Humans have agency; they act on their environment based on their own understanding of their situation. Seeing CLHSs as complex systems has implications for understanding and changing them.
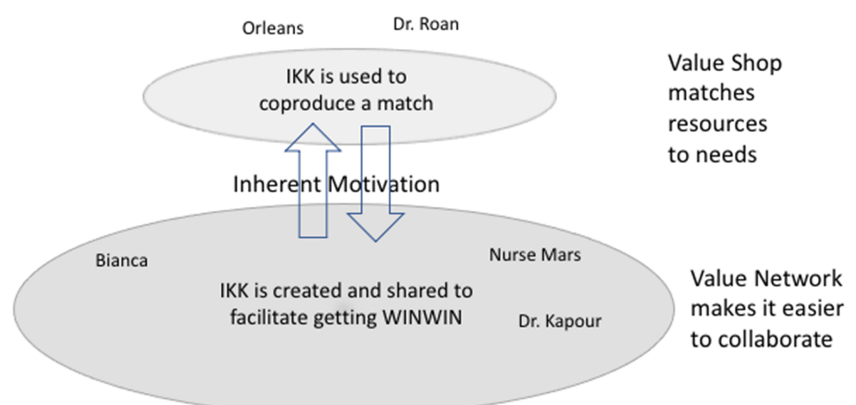
1.3 | CLHSs facilitate networked coproduction

A fundamental mechanism[23,24] of improving health is matching treatments, services, and care (both in and outside the clinical realm) to Orleans' and other persons' needs and goals as they evolve over the course of an experience with an illness. CLHSs can be thought of as systems that facilitate this matching. Appropriate combinations of treatments, services, and care are not only the result of clinical encounters. Over the course of a chronic illness, all patients are active agents[25] who may use a variety of resources at and between clinical encounters.[26,27] To make a good match, it is necessary to have well-defined needs and goals,[28] a system for informing, making,[29] and optimizing[30-32] decisions about the match, accessible resources, and the ability to update this matching as new information or needs arise.

At the level of individuals, matching happens as a result of coproduction of good care involving patients, families, and clinical care teams (Figure 1).[33-35] A good match relies on the work of both patients and clinicians, like Orleans and Dr. Roan, to collaborate to coproduce IKK—information (eg, data on clinical symptoms), knowledge (eg, which treatments work for whom), and know-how (eg, how to reliably achieve and adhere to evidence-based care) for informing, choosing, and implementing the match.

Value creation configurations can impact the effectiveness of co-production and matching.[36] Healthcare services take various organizational configurations to produce value for patients.[36] The dominant organizational form in healthcare is a consultative model known as a

FIGURE 1 Schematic illustrating a CLHS. Changing the system, rather than people, unleashes inherent motivation toward a shared purpose. Using an actor-oriented organizational architecture, a CLHS becomes a value network, facilitating the production and sharing of IKK (information, knowledge, know-how) for getting WINWIN ("What I need, when it's needed"). This IKK is available in the clinical encounter (the value shop), facilitating coproduction of a match between needs and resources

"value shop," in which value is created through "mobilizing resources and activities to resolve a particular customer problem" (p. 414).[37] When Orleans has a clinic visit with Dr. Roan, the value shop configuration addresses clinical care through highly customized matching of resources to needs by clinicians and care teams, often using sophisticated information systems. The value shop configuration is prevalent throughout primary and specialty care. Hospitals also employ this value creation logic to provide treatment in support of patient needs, as when individualized treatment plans are developed, deployed, and modified during an inpatient stay.

Even with well-defined patient goals, needs, and accessible resources, the huge number of possible resource-by-need combinations easily overwhelms the knowledge available to individual or small groups of experts. This problem will only be exacerbated as the pace of knowledge creation accelerates (eg, advances in personalized medicine, through genomics, remote sensors, and other innovations). Moreover, some resources (eg, the lived experience of managing a colostomy bag[38]) are simply not available to clinicians. The overwhelming variety of possible matches, as well as the diversity of resources that patients need, invites consideration of new models of value creation.[39]

The value shop logic can be enhanced via a "value network" in which value is created by facilitating connections among actors as well as resources.[36,37] This organizational configuration is ubiquitous in other industries (eg, Wikipedia, Facebook, Travelocity, Lyft, Monster.com). In a value shop, doctors and patients can bring only their own resources to solve the matching problem. A CLHS uses value network logic to facilitate more flexible and dynamic connections and exchange between and among actors and resources.[36,40] A value network can thus allow and facilitate needed customization beyond what is often possible in an unconnected value shop configuration. A value network also makes it possible for resources to be more widely available by connecting individuals, organizations, and data. Bianca's expertise can be brought to bear, as can the data generated by Dr. Kapour's app. In a value shop, information about what works for the individual might not be shared beyond the patient-clinical team dyad. Using a value network configuration, data and knowledge generated at each clinical encounter can be shared with the rest of the network, where it can be accessed and acted upon by other patients and clinicians.[41] Orleans' data from Dr. Kapour's app could inform Nurse Mars' consultation with a different patient in a different city. Patients and families may be able to access information from other patients and families,[27] and clinicians and care teams can do the same,[42] all using data shared and aggregated across people and organizations. In this way, the network configuration recapitulates the value shop at scale. This connectivity also allows the value network to facilitate resource creation and sharing outside of the clinical encounter, for example, via peer-to-peer interactions, information from remote sensors, and through other service providers. Ultimately, more IKK is available so that people get WINWIN.

A potential concern in any value network configuration is the relevance and rigor of the resources available. What if patients (or clinicians for that matter) create and spread bad information? How might we ensure that misinformation or disinformation is not generated and spread, with potentially calamitous results? First, it is important to recognize that patients and clinicians, as active agents, seek information and other resources from a variety of sources. Over a decade ago, Pew Research Center's Internet & American Life Project documented that although clinicians are the first choice for most people for information about health concerns, online sources, including advice from peers, are a significant source of health information in the US.[43] Second, it is instructive to recognize the different types of resources needed by patients and families.[27] Beyond technical and medical information, practical advice and emotional support are also needed. Given this reality, there are a variety of mechanisms possible to ensure the relevance and rigor of available resources and to mitigate the risk that such information would be spread. One way is to build a review process into the development of the resource. For example, in ImproveCareNow, the Patient Advisory Council (PAC) has a system for generating patient-led resources (eg, toolkits on nutrition and IBD, transitioning to college, body image concerns, or educational and occupational accomodations), with a review function distributed across a variety of actors within the network including clinicians and the broader community.[44] A second way is to create and sustain cultural norms (eg, integrity, transparency, pro-science) inconsistent with the propogation of misinformation. Such cultural infrastructure[45] makes it more likely that the community will develop behaviors (eg, asking peers to cite sources, considering accuracy before reposting[46]) that mitigate against propogation of misinformation. CLHS culture typically views the creation and sharing of resources among patients as supporting, rather than supplanting, the clinical relationship by bringing more IKK to the clinical relationship.

1.4 | Mechanisms of action at the individual and organizational level

Describing coproduction and the value network logic begs the question of the underlying mechanisms: What makes them work? Coproduction relies on engagement, by which we mean the degree to which people in all roles (patients, families, clinicians, researchers, others) are involved in the CLHS to utilize, create, and/or share the information, knowledge, and know-how for improving care and outcomes.[47] Engagement varies as people become more and less involved. People can be engaged as participants, using existing information and resources (eg, reading a blog post, using clinical decision-making tools, signing up for a research study, tracking on Dr. Kapour's app), as contributors by making the resources better (eg, writing a blog post, refining clinical decision tools as Nurse Mars has done), or take ownership by creating new resources (eg, a new research study, patient resource, or clinical tool). As more people (patients, families, clinicians, researchers) are engaged in contributing to existing resources or creating and sharing new ones, more and better resources will be available.

The value network can be understood as enabled by an actor-oriented architecture.[40] With enough actors (people, institutions) motivated and able to self-organize; a commons where they create, store, and share resources; and structures, processes, and protocols that facilitate multiactor collaboration, resources are produced and shared across the CLHS, thus facilitating the individual patient-treatment matching process at scale.

The mechanisms underlying the actor-oriented architecture and engagement are similar—unleashing inherent motivation to enable contribution and sharing toward the purpose of better health for individuals and communities. A large body of social and behavioral science suggests that people tend to be prosocial and motivated by affiliation, autonomy, and mastery.[48] People want to make a difference (contribute in positive ways to health) and will do so if their situation allows this. Non-market-based production[49] is a term used to describe the fact that people will do things for reasons other than money. Examples outside healthcare are widespread, from parent–teacher associations to open source software (eg, R, Linux) to Yelp and the Audubon Christmas Bird Count. Building systems (structures and processes) to make it easier for people to collaborate to improve health unleashes this inherent motivation.

The existing healthcare service system limits the ability of people to act upon these motivations. Well-intentioned, competent people currently function within a system that impedes rather than empowers stakeholders to apply their inherent motivation and expertise to solving challenging problems that match resources to needs.[50] Changing outcomes requires changing the system; CLHSs such as Learning Networks intentionally change the system in such a way as to enable participants to better collaborate to make this match. CLHSs focus relentlessly on outcomes, create infrastructure and processes to facilitate sharing and collaboration, and promulgate methods to supporting continuous improvement and research to provide a way of solving problems and learning together.

2 | DISCUSSION

CLHSs have been replicated, within pediatrics, across chronic conditions (eg, Reference 4), inpatient safety,[8-11] preterm birth,[3] and community health,[12] suggesting that these are a class of scientific phenomena that can be studied systematically. We assert that an appropriate scientific approach is to view CLHSs as complex systems.[51-53] In complex systems, the whole is more than the sum of the parts—the interaction among the parts creates emergent phenomena. In CLHSs, the system's parts are people (like patients, clinicians, administrators), institutions (like hospitals, insurance, and pharmaceutical companies), and assets (eg, databases, medicines, clinic space). CLHSs provide an environment and infrastructure that enable these parts to interact in new ways to facilitate better care and outcomes. This is accomplished, we assert, by making it easier for more "actors" to create and share resources that can be used to coproduce better matching of resources to needs. Powering this system is the inherent motivation of all stakeholders; by aligning goals and making it easier

to express this inherent motivation, CLHSs enable nonmarket production toward these goals. Implicit to this framework is collaboration; for this reason, we term such organizations *Collaborative* Learning Healthcare Systems (CLHSs).

The conceptual framework of CLHSs presented in this work is distinct from other descriptions of LHSs, which tend to emphasize big data or vertical health systems within firms. First, they are arrangements consisting of people across institutions who voluntarily organize around shared goals, suggesting that Learning Healthcare Systems can exist beyond integrated vertical health systems. Second, they foreground the people in the system and highlight the role that social constructions have on creating impact; CLHSs are more than registries of big data. Third, their goals are tripartite—they are organized around clinical care, improvement, and research. This integration of effort sets them apart from networks focused only on QI or research. Fourth, and perhaps most importantly, CLHSs make it possible for more people of all stakeholder types to be part of the work of improving outcomes; they are platforms for facilitating collaboration at scale.

2.1 | Social and technical challenges in CLHSs

Social/organizational challenges to CLHS development and scale exist. Governance of CLHSs requires an understanding of the mechanisms underlying value creation, as well as an appreciation of the scholarship and practice involved in stewarding a commons.[54] Policies about privacy, data standards,[55] ethics,[56] intellectual property,[57] and others must be developed to facilitate sharing and collaboration. Potential problems such as free-riding (taking advantage of others' contributions) and other opportunistic behaviors must be addressed.[58] The network organizational form requires norms of collaboration and trust, new ways of leading, and specific leadership competencies.[36] Leaders must promote these norms, lead through influence and by stimulating new connections, and develop new leaders so that such systems can continue to grow and develop. There are substantial financial and human resources required to enable CLHSs; funding for these and efforts to reduce both fixed and variable costs are required. Scientific norms regarding the degree of evidence required for decision-making or the quality of data required for knowledge creation must be established. The rigor and relevance of resources posted to the commons must be ensured. Increasing the number of people aware of and involved in CLHSs and facilitating increasing levels of contribution is an ongoing effort required to scale up. Equity must be directly addressed, incorporating a range of stakeholders so that these advances do not widen, but rather reduce existing health disparities. Especially important are ways to change the system to make it possible for people with fewer resources or who face systemic racism to be able to benefit from CLHSs.

Technical challenges, likewise, merit consideration. Data needed to generate evidence and reusable technology platforms are required to gain an economy of scale. Systems engineering to maintain and

upgrade the infrastructure is key. Data streams from new technologies will require linkages among existing data repositories. New analytic approaches and artificial intelligence will solve and create both technological and social challenges.

2.2 | Implications for CLHS research

If we are to transform the US healthcare system into a CLHS or collection of CLHSs, this conceptual picture suggests a broad agenda spanning basic through translational research. Analogous to NIH's NCATS's translational science spectrum (https://ncats.nih.gov/translation/spectrum), we can think of CLHS basic science (eg, to reveal fundamental CLHS mechanisms), preclinical research (eg, to study potential implications of these fundamental mechanisms through model CLHS interventions), clinical research (eg, to test the safety and effectiveness of CLHS interventions), and clinical implementation research (eg, to increase the adoption of proven CLHS interventions). Representative research needs include:

- Descriptive studies of existing CLHSs to describe the range of CLHS variation and the boundaries of such systems and understand how CLHSs develop and adapt over time. For example, are there a set of features all CLHSs have in common or a set of developmental stages they progress through from design to maturity? Are there differences between CLHSs focusing on primarily pediatric conditions and those focused on primarily adult conditions?
- Identifying and describing key mechanisms of action at the CLHS level and at the clinical level. For example, what is the role of "engagement," in the function of the CLHS? Is it the same as how engagement might function at the clinical encounter? How does increased resource exchange (sharing) affect CLHS function? Is there a difference across information, knowledge, and know-how in matching resources to needs? How are needs represented and understood? What could go wrong in such matching and how might errors be mitigated? Is all sharing equally important or does it matter what is shared or with whom? Does network structure (eg, who is connected to whom) matter, and how?
- Understanding the requirements and limitations of supporting infrastructure. What supporting infrastructure is required for CLHSs to function appropriately? Are there processes and policies (eg, data models, intellectual property policies, ethics, standard contracts) that need to be in place to promote collaboration in such systems?
- Understanding conditions necessary for creating a CLHS. Is there a parsimonious set of "rules" for creating a CLHS in which connectivity and collaboration flourishes? A central challenge is to identify parameters or sets of parameters[59] such as policies and procedures, that might sufficiently change the interactions among components of the healthcare system to induce a shift away from the current system of healthcare toward a CLHS.

- Developing measures and model systems. How do we define "engagement" or "collaboration" and how might we use such measures to observe and better understand CLHSs? How might we construct and use model systems (eg, a computational model[60]) for studying CLHSs?
- Exploring the impact of interventions targeted at elements of the actor-oriented architecture. What are effective research designs for understanding the impact of interventions? How might we characterize strategies for increasing CLHS effectiveness and efficiency[61]? What are the conditions under which CLHSs thrive and scale and how might these strategies might vary based on initial organizational or clinical conditions? What is the impact of CLHS on cost and value?
- Understanding the impact of the policy environment on CLHSs. What are the financial incentives for clinicians, healthcare systems, and payers and how might these affect CLHS proliferation? Are there policies that might reduce the risks healthcare systems might incur by sharing data or information or that would encourage evidence generation?

The framework described in this commentary should be considered as a starting point for understanding CLHSs and a set of hypotheses to be tested. It is our hope that articulating this theory will enable more patients, scholars, practitioners, and policy makers to collaborate in achieving the vision of a Learning Healthcare System.

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