Type: Perspective

How Can Reasoned Transparency Enhance Co-Creation in Health Care and Remedy

the Pitfalls of Digitization in Doctor-Patient Relationships?

Abstract

This article addresses transparency in the current era of digital co-creation between healthcare professionals and patients. The concept of reasoned transparency is presented as a potential tool to guide the development of digital co-creation that is rapidly growing. The aim was to reflect on how doctors can apply transparency in their daily practice, following the shift from paternalistic to more collaborative relationships. On the one hand, our contribution indicates ways to take advantage of the existing digital tools to improve efficiency and increase patient trust, including the latest trend of artificial intelligence. On the other hand, this article identifies pitfalls of digitization and proposes reasoned transparency as remedy for the challenges rose by artificial intelligence. As a result, this perspective article tackles the issue of maintaining trustful and high-quality relationships between doctors and patients, increasingly challenged by the dissemination of online information and the pressures on healthcare professionals' accountability towards patients and the general public.

Keywords: Digitization; Transparency; Co-Creation; Artificial Intelligence.

Introduction

What are the pitfalls of applying transparency in the medical world, and how should doctors address this issue in their daily practice? These questions are important in the current era of data sharing and full disclosure. Transparency has for some time been a buzzword in healthcare management, where openness policies are frequently proposed as the cure to governance problems. In this sense, the opacity traditionally characterizing the healthcare domain has been increasingly questioned, especially regarding quality reporting issues. This change is the result both of ethical considerations (conflicts of interest, clinical trial conditions) and economic incentives, driven by the need to improve the healthcare system's efficiency. Moreover, transparency has been claimed in health care to improve clarity, to increase patient trust, and to induce better long-term outcomes by improving quality of care.

Reflection about transparency has to be extended to daily medical practice, in which doctors are advised to openly discuss treatment, medication, or the disease progress with their patients. This development is guided by the concept of patient empowerment, shifting from a paternalistic model towards the growing involvement of patients through medical explanations, informed consent, and decision sharing. It falls under the broader notion of co-creation, which implies more frequent interactions as well as the sharing of resources and responsibilities with the aim of producing more efficient and trustworthy health solutions and outcomes.^{5,6} Co-creation is understood here as a process to provide better care service and increase the perceived value of the treatment by the patients. In this regard, maximization of care quality is ensured by frequent interactions between doctors and patients, based on active collaboration rather than passive involvement.⁷ Co-creation should be regarded as a goal as well as a result of this shift from one-way communication to increased interaction. While digitization and the recent trend of artificial intelligence (AI) offer new opportunities to enhance the patient-doctor relationship, there are also pitfalls related to this technological evolution. This perspective article questions the implementation of transparent medical practice in an increasingly digitized environment, and proposes reasoned transparency as a remedy for the challenges highlighted in both the literature

Transparency and accountability in health care

The transparency movement echoes the general call for accountability. Doctors are *held to account* by their hierarchy, their patients, the general public, politicians, and the payers; at the same time, they have to *take into account* patients' opinions and decisions. Consequently, they are subject to vertical and horizontal forms of accountability, under growing pressure from both managers and patients. In the surgical world, this transparency quest has also pushed hospitals and surgeons in several countries to closely monitor their complication rates and make them publicly available. A potential negative consequence is that patients or people outside the healthcare system consulting the raw numbers lack important elements of context that are essential before any interpretation. For example, a particular hospital or surgeon may display higher complication or mortality rates due to the type of polymorbid and frail patients treated and operated on. The need for sound explanations to foster patients' understanding has been labelled in other contexts (government-citizen relations) as reasoned transparency. Applied to healthcare issues, this concept enables better patient choices and decisions, assuming that it will

and practice, including data privacy, self-medication, or trust in the patient-doctor relationship.8

1 increase people's knowledge and understanding of the functioning and actions of public health

2 organizations and professionals.

Transparency has been addressed in different ways, depending on the context considered. In Switzerland, a new section of the *Law on Therapeutic Products* that came into force on January 1, 2020, introduces integrity and transparency obligations for professionals prescribing medication, forcing doctors to systematically report their activities. This law aims at encouraging patients to engage more deeply with the medical community regarding their medication and treatment. Similar legislation has been adopted earlier in some countries. An example is the U.S. *Physician Payment Sunshine Act* passed in 2013 and due to be extended to physician assistants and advance practice nurses in 2021-22. This development, in addition to being of interest to regulators and policymakers, gives patients more precise knowledge of doctors' financial ties with manufacturers or drug companies. This is crucial, given that patients will increasingly do research on medications and providers. Furthermore, payment disclosures are of importance as it was estimated in a 2007 study that 94% of U.S. doctors had links with pharmaceutical companies. In addition to deepening the patient-doctor relationship, these new legal requirements help advance the debate on external pressures on conflict of interests and the general functioning of the health care system.

The effect of digitization on transparency and co-creation practices

In medicine access to information and to healthcare providers is key for successful transparency.¹² Lately, this increasing need for transparency and accountability has been reinforced by the development of new technologies. In this sense, digital medicine might improve interoperable access.¹² Regarding the relationship between doctors and industry, traceability has to be enhanced, potentially leading to more accountability. Better treatment monitoring and follow-up may be required by patients, based on the creation of an electronic medical record, which can be transmitted to other hospitals and patients themselves. Moreover, further technological developments may reduce costs and save time through co-creation practices. Vaccination certificates to be filled online, with multiple, personalized predetermined choices, provide a good example of what can be co-created electronically, involving the patients to ease the process, and save time and money. In addition, transparency helps improve patient safety via incident reporting.¹³ However, in terms of online access to patient data and reporting, great disparities between institutional and non-hospital (family physicians, pharmacy, etc.) settings still remain and should not be overlooked. In addition, transparency of

1 data needs safeguards to protect patient confidentiality. With digitization, it is important to have 2 systems such as blockchain or identification access management to protect the security of data. 3 Co-creation is a multifaceted notion and refers to distinct processes: e.g., relationships between 4 suppliers and customers to improve health care (digital) solutions, horizontal collaborations 5 within a hospital to improve treatment, or mutual decision between patients and their physician to deliver better care quality.¹⁴ Here, we prefer the latter facet of co-creation since our focus is 6 7 on the relationships between patients and healthcare professionals, especially doctors. 8 Digitization has influenced the dynamics of co-creation through widespread access to the 9 Internet and, consequently, access to large amounts of information. While doctors remain the 10 experts regarding clinical knowledge, patients have now authority over their own personal preferences and values. 15 As a result, the democratization of decision reflects a cultural change, 11 which results from the "inevitably disruptive effects of citizen-empowering technological 12 change". 16 Although praised in many settings, this evolution of the patient-doctor relationship, 13 bolstered by digital technologies, is yet to be implemented in most cases. 14 15 As one of the latest technological developments, AI tends to reinforce the ambition of fostering a patient-centered approach. ¹⁷ In general, AI raises great expectations since it holds the potential 16 17 to reduce transaction costs, to provide ever vigilant tools, to provide physicians with up-to-date 18 information on a timely basis and, most importantly, to help reduce therapeutical errors that can happen in human clinical practice. 18 This global enthusiasm for AI in healthcare is in line with 19 20 the massive investments in the domain, reaching around \$8.5 billion, including all big tech companies, insurers, startups, pharmaceutical and medical-device firms.¹⁹ In China, more than 21 22 300 million users have registered to the leading health-management platform, called Ping An's 23 Good Doctor.¹⁹ 24 AI relates to multiple services, tools and layers. As a form of digital innovation, it includes 25 facilitated collection of a wide range of patient data, expansion and further creation of datasets, 26 accelerated development of logical capability through physical machinery and devices, and 27 improved services to extend diagnoses, partially based on these devices.²⁰ Here, we focus on 28 the latter service layer since it is more closely linked to the patient-doctor relationship. For 29 instance, at-home treatments are supported by smartphone applications in selected cases, and 30 treatment may be derived from predefined algorithms. Explainable AI refers to the notion of understandable results of AI.²¹ This group of methods 31 aims to render the solutions given by AI more comprehensible to humans. In medicine, 32 33 explainable AI is of importance, because deep learning results often are black-box predictions

that cannot be explained to clinicians. These black-box predictions lack transparency. The challenge now is to find the best AI model that can be precise and powerful enough but at the same time explainable and transparent without being too simplistic.²² In that sense and in the context of co-creation, explainable AI in medicine could serve as support of co-creation by contributing to the proposed concept of reasoned transparency. For example, it is of value for the clinician to know exactly which individual parameter play an important role in an AI prediction.²² Explainable AI is a powerful tool and means to increase transparency and trust in a co-creation model in medicine.²³ A further challenge for the clinician will be to popularize not only the results of AI and ML but also the mechanism behind it. This will require pedagogical skills and specific knowledge of AI and ML. The example of at-home treatment using smartphone applications goes one step further than transparency since it provides patients with a decision to make by themselves, for themselves. Paradoxically, such a system could reverse the current trend of deeper patient involvement in the therapeutic relationship. It could also broaden the gap between patients and physicians should the latter be replaced by devices, designed and perceived as outperforming healthcare professionals, thereby creating an 'automation bias'. 20 Such a change would certainly damage the patient-doctor relationship. At the same time, it would undermine the implicit promise of healthcare systems: to exercise good judgment, partially based on the patients' needs, to deliver high quality care. AI and machine learning (ML) induce other significant challenges: importance of safeguards, risk of bias, inequity, effects on patients, legal concerns, and societal issues (trust decline or decreased value of patient choice).²⁴ Several methods or safeguards have been or can be proposed to respond to these abovementioned risks of AI and ML. AI results and predictions should be first and foremost accurate.²⁵ It should therefore be assessed on outcomes and be proven to improve patient outcomes.²⁵ In that sense, at that moment, AI should be proposed in research settings and strong evidence on outcomes should be published. Explainability of AI and mitigation of bias should be clearly emphasized.²¹ Strict regulations and legal directives should also be created and enforced. Finally, potential conflicts of interests of AI developer companies should be exposed. In spite of these pitfalls, AI represents a major technological advance that will definitely enrich and help the medical world. With a capacity well beyond human brain capacities, AI may soon bring undeniable help and support for the diagnosis or treatment of patients, provided it is guided by healthcare professionals to explain and contextualize plain results and to discuss the existing therapeutic options in a trusting patient-doctor relationship. This last point is crucial:

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the nature of AI systems should remain assistive. ²⁶ In this sense, human interactions should not 1 2 be fully replaced by digital devices; these tools are modeled for providing support for clinicians' decision, which should be reached through a constructive dialogue with patients.²⁷ This is how 3 4 we envisage co-creation of better quality care thanks to exchanges based on reasoned 5 transparency, capitalizing on the opportunities offered by an increasingly digitized work 6 environment. 7 However, digitization, if uncontrolled, faces another challenge. It may seriously endanger the 8 dynamic of transparency, accountability and trust in patients' experience with healthcare. 9 Taking a closer look, applications are a black box, raising questions as to who or what will 10 finally be held accountable for decisions taken by machine processes. This points especially to 11 the difficulty of establishing a regulatory framework. In the UK, for instance, the Information 12 Commissioner (in charge of public transparency and data protection) ruled out the usage of an application designed by Google DeepMind, which could alert patients at risk of renal diseases.²⁸ 13 14 Also related to data privacy, patients may refrain from sharing their data in the absence of a 15 clearly established surveillance body, which ensures that such data will not be used to serve 16 commercial purposes or health insurance interests. In this regard, health care does not differ 17 from other domains and policies, where transparency and accountability are regarded as key principles to overcome this problem. In most cases, de-identification techniques are also 18 proposed to ensure confidentiality.²⁹ The main challenge of transparency is probably privacy 19 20 maintenance. New technologies such as blockchains or identification access management might 21 help combining these two issues. Blockchain technology with specific encryption and 22 protection mechanisms offers diverse layers of transparency. Moreover, identification access 23 management permits to keep data secure. These two examples of technological developments 24 could be seen as safeguards that could be used without precluding transparency. A major 25 difference in the medical world though: excessive transparency endangers medical privacy, the 26 sacred principle underlying the patient-doctor relationship. 27 Although informed by medical expertise and knowledge, this new, technological-oriented 28 approach to treatment will not solve a problem already faced by doctors and patients discussing 29 therapeutic options: technical issues remain better understood by specialists, who can then provide contextualized advice. In this sense, even though co-creation practices will certainly 30 31 turn more digital with the development of AI, patients will still have a deficit of information, 32 which can lead to dramatic consequences (this is already the case, for example, when people 33 prefer to self-medicate based solely on information retrieved online).

AI is expected to overcome this last challenge by providing timely and accurate answers to people through algorithms. Consequently, this process may disrupt the exchanges between doctors and patients, currently positively evolving from one-way communication to active involvement of patients in their care. For example, treatment options following genetic testing have to be discussed and decisions have to be taken in concert with the patient. Through a detailed discussion, information can be shared more deeply. Such reasoned transparency may be seriously damaged by the dictatorship of algorithms, thus unraveling current efforts to establish more qualitative relationships between medical staff and patients, including personal feelings and psychological monitoring. Conversely, processing of information thanks to AI may allow additional time to physicians, which can be spent to have fruitful discussions with the patients, enabling doctors to better understand the patients' values and deliver individualized care in a better way.³⁰ In this vein, digital tools, including AI devices, and reasoned transparency do not seem to be automatically at odds, and may well lead to trustful relationships between patients and their doctors, sustained by mutually beneficial co-creation practices.

Conclusion

In conclusion, reasoned transparency should therefore be the concept to develop in the near future to avoid the pitfalls of the upcoming digitization of healthcare. This points to the necessity of empowering patients through a strategy of risk-benefit communication, including the opportunities and limitations of digital applications for patient treatment. Moreover, doctors should endeavor to contextualize all results and treatments since most digital tools, and AI in particular, do not explain the recommendations made. Consequently, trust may be eroded or compromised due to the potential clash between treatment recommendations online, physician judgment and patient autonomy of decision.³¹ Therefore, reasoned transparency invites physicians to communicate abundantly about the usage of digital tools and devices, reassure patients about data confidentiality, increase patient knowledge about the treatment, and ensure a favorable environment to foster co-creation practices.

All told, the current fascination with AI, which holds out great potential while giving the

illusion of full transparency, must not undermine the long-standing bonds of trust between

healthcare professionals and patients, which should remain the cornerstone of the therapeutic

relationship. This point seems even more important in our era, characterized by an increasing

reliance on technology, performance and online information/tools, no matter how misleading.

12 References

- 3 1. Levay C, Waks C. Professions and the Pursuit of Transparency in Healthcare: Two
- 4 Cases of Soft Autonomy. Organization Studies. 2009 May 1;30(5):509–27.
- 5 2. Pronovost PJ, Wu AW, Austin JM. Time for Transparent Standards in Quality
- 6 Reporting by Health Care Organizations. JAMA. 2017 22;318(8):701–2.
- 7 3. Goupil B, Balusson F, Naudet F, Esvan M, Bastian B, Chapron A, et al. Association
- 8 between gifts from pharmaceutical companies to French general practitioners and their drug
- 9 prescribing patterns in 2016: retrospective study using the French Transparency in Healthcare
- and National Health Data System databases. BMJ. 2019 Nov 5;367:16015.
- 4. Oettgen P. Transparency in Healthcare. EBSCO Health, DynaMed Plus.
- 12 5. Frow P, McColl-Kennedy JR, Payne A. Co-creation practices: Their role in shaping a
- health care ecosystem. Industrial Marketing Management. 2016 Jul 1;56:24–39.
- 14 6. Lusch RF, Vargo SL, Tanniru M. Service, value networks and learning. J Acad Mark
- 15 Sci. 2010 Feb 1;38(1):19–31.
- 16 7. Lee D. Effects of key value co-creation elements in the healthcare system: focusing on
- technology applications. Serv Bus. 2019 Jun 1;13(2):389–417.
- 18 8. Hughes G. The promise of conversational AI in helping restore the doctor-patient
- 19 relationship [Internet]. MedCity News. 2020 [cited 2020 Dec 5]. Available from:
- 20 https://medcitynews.com/2020/09/the-promise-of-conversational-ai-in-helping-restore-the-
- 21 doctor-patient-relationship/
- 9. Birdas TJ, Rozycki GF, Dunnington GL, Stevens L, Liali V, Schmidt CM. "Show Me
- 23 the Data": A Recipe for Quality Improvement Success in an Academic Surgical Department. J
- 24 Am Coll Surg. 2019;228(4):368–73.
- 25 10. Coglianese C. The Transparency President? The Obama Administration and Open
- 26 Government. Governance. 2009;22(4):529–44.
- 27 11. Campbell EG. Doctors and drug companies--scrutinizing influential relationships. N
- 28 Engl J Med. 2007 Nov 1;357(18):1796–7.
- 29 12. Lehne M, Sass J, Essenwanger A, Schepers J, Thun S. Why digital medicine depends
- 30 on interoperability. NPJ Digit Med. 2019 Aug 20;2(1):1–5.
- 31 13. Fukami T, Uemura M, Nagao Y. Significance of incident reports by medical doctors for
- 32 organizational transparency and driving forces for patient safety. Patient Saf Surg. 2020 Apr
- 33 16;14(1):13.
- 34 14. Leone D, Schiavone F, Appio FP, Chiao B. How does artificial intelligence enable and

- 1 enhance value co-creation in industrial markets? An exploratory case study in the healthcare
- 2 ecosystem. Journal of Business Research [Internet]. 2020 Nov 19 [cited 2020 Dec 5]; Available
- 3 from: http://www.sciencedirect.com/science/article/pii/S0148296320307517
- 4 15. Aminololama-Shakeri S, López JE. The Doctor-Patient Relationship With Artificial
- 5 Intelligence. Am J Roentgenol. 2019;212(2):308–10.
- 6 16. Dowie J, Kaltoft MK. The Future of Health Is Self-Production and Co-Creation Based
- 7 on Apomediative Decision Support. Med Sci. 2018 Aug 22;6(3):66...
- 8 17. Kuan R. Adopting AI in Health Care Will Be Slow and Difficult. Harvard Business
- 9 Review [Internet]. 2019 Oct 18 [cited 2020 Jan 26]; Available from:
- 10 https://hbr.org/2019/10/adopting-ai-in-health-care-will-be-slow-and-difficult
- 11 18. Jiang F, Jiang Y, Zhi H, Dong Y, Li H, Ma S, et al. Artificial intelligence in healthcare:
- past, present and future. Stroke Vasc Neurol. 2017 Dec;2(4):230–43.
- 13 19. Transforming healthcare with AI: The impact on the workforce and organizations
- 14 [Internet]. [cited 2020 Dec 11]. Available from:
- 15 https://www.mckinsey.com/industries/healthcare-systems-and-services/our-
- 16 insights/transforming-healthcare-with-ai
- 17 20. Arora A. Conceptualising Artificial Intelligence as a Digital Healthcare Innovation: An
- 18 Introductory Review. Med Devices (Auckl). 2020;13:223–30.
- 19 21. Gunning D, Stefik M, Choi J, Miller T, Stumpf S, Yang G-Z. XAI-Explainable artificial
- 20 intelligence. Sci Robot. 2019 Dec 18;4(37):eaa7120.
- 21 22. Lauritsen SM, Kristensen M, Olsen MV, Larsen MS, Lauritsen KM, Jørgensen MJ, et
- 22 al. Explainable artificial intelligence model to predict acute critical illness from electronic
- health records. Nature Communications. 2020 Jul 31;11(1):3852.
- 24 23. Selbst AD, Powles J. Meaningful information and the right to explanation. International
- 25 Data Privacy Law. 2017 Nov 1;7(4):233–42.
- 26 24. Hajjo R. The Ethical Challenges of Applying Machine Learning and Artificial
- 27 Intelligence in Cancer Care. In: 2018 1st International Conference on Cancer Care Informatics
- 28 (CCI). 2018. p. 231–231.
- 29 25. Carter SM, Rogers W, Win KT, Frazer H, Richards B, Houssami N. The ethical, legal
- and social implications of using artificial intelligence systems in breast cancer care. The Breast.
- 31 2020 Feb 1;49:25–32.
- 32 26. Habli I, Lawton T, Porter Z. Artificial intelligence in health care: accountability and
- 33 safety. Bull World Health Organ. 2020 Apr 1;98(4):251–6.
- 34 27. Lalmuanawma S, Hussain J, Chhakchhuak L. Applications of machine learning and

- 1 artificial intelligence for Covid-19 (SARS-CoV-2) pandemic: A review. Chaos Solitons
- 2 Fractals. 2020 Oct;139:110059.
- 3 28. Balthazar P, Harri P, Prater A, Safdar NM. Protecting Your Patients' Interests in the Era
- 4 of Big Data, Artificial Intelligence, and Predictive Analytics. J Am Coll Radiol. 2018;15:580–
- 5 6.

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- 6 29. Kostkova P, Brewer H, de Lusignan S, Fottrell E, Goldacre B, Hart G, et al. Who Owns
- 7 the Data? Open Data for Healthcare. Front Public Health. 2016;4:7.
- 8 30. Nagy M, Sisk B. How Will Artificial Intelligence Affect Patient-Clinician
- 9 Relationships? AMA J Ethics. 2020 01;22(5):E395-400.
- 10 31. Nundy S, Montgomery T, Wachter RM. Promoting Trust Between Patients and
- Physicians in the Era of Artificial Intelligence. JAMA. 2019 Jul 15; Epub.