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Co-care: Producing better health outcome through interactions between patients, care providers and information and communication technology

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Abstract

The demands on healthcare are shifting, from caring for patients with acute conditions managed in a single-care episode to caring for patients with chronic and often complex conditions. With this shift comes a recognition that healthcare requires an interaction between patients and care providers, and of the interdependencies between these actors for achieving a positive outcome – that the results are co-produced. This paper introduces co-care, which stresses that the role of healthcare providers is to complement people's own resources for managing their health so that patients' and healthcare providers' resources combined leads to the best possible outcome. This is done using tools and artifacts such as information and communication technology that enable knowledge to be created, shaped, shared and applied across the actors. Thus, in co-care, knowledge is not attributed to a single entity but distributed between them in line with the theory of distributed cognition. To put co-care into practice, several challenges must be addressed. This includes moving from profession-centeredness to patient-centeredness and from approaching care as a transformation of input to products to viewing care as linking needs and knowledge, as well as a substantial attitude and behavior change across healthcare stakeholders.

Keywords

co-creation, coproduction, health information technologies (HIT), informatics, information and communication technology, management, patient-centeredness

Introduction

Sitting at the physiotherapist's office the other day, frustrated with the lack of sufficient progress in the rehabilitation of a troublesome hip, I had a personal epiphany related to one of the major challenges for healthcare and healthcare management. The healthcare provider, embodied here by the physiotherapist, cannot be held solely accountable for the result of this healthcare episode. What I – the patient – do matters, and the result is the product of our mutual contributions and collaboration. Like about 80% of those who utilize health services, my health problems are not of an acute, episodic type that the healthcare professional can cure. Rather, he needs to complement the resources I bring (including knowledge, skills and abilities) with those I don't (yet) have that, when combined, will enhance the management of my condition – a condition that takes place 24–7 rather than just during my visits to his office. And to manage this effectively, we also need good data that can inform our decisions. In this paper, I will outline the current societal changes that have had, and will have, a tremendous influence on the future of healthcare services and management. Based on these driving forces for change, I will argue that co-production of results taking place in health service systems supporting patient self-management through information and communication technology – co-care – will hold a prominent place in the future of healthcare. Finally, I will discuss the implications of these

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changes on healthcare management practice and research.

Driving forces for change towards co-production of care

Healthcare has undergone extraordinary development during the past 50 years, with a fast medical-technical development that prolongs and improves life. Combined with aging populations, the number of people with chronic, multiple conditions with a predominance of non-communicable diseases (i.e. lifestyle related illnesses) is increasing.[1] So are costs, at a pace that by far exceeds the growth in GDP, which is not sustainable in the long run.[2] As the increase in medical costs is driven primarily by the increase in chronic illnesses, and with lack of coordination of care as one of the cost-drivers,[2] coordinated approaches have been identified as a way to reduce costs without reducing quality.[3] In fact, coordinated approaches offers a way from organization of care around single-organ, single-episode care to a patient goal orientation that fits much better for the chronic care that patients with multimorbidities and lifestyle related illness need.[1,4,5]

In addition, in order for medical interventions to work, they generally require that patients take action – at a minimum, following the ordinations but more often, much more than this. For chronic and lifestyle diseases in particular, self-management is necessary to achieve good health outcomes.[5] In fact, the question is not *whether* but *how* people self-manage their chronic condition, as their influence on the management of it is inescapable.[6] This calls for a collaborative relationship between healthcare professionals and patients.[6] Also, as information is more accessible, patients are becoming increasingly knowledgeable, changing the interaction pattern between them and healthcare professionals.[7] For example, patient access information about diagnosis and available treatments before visiting a healthcare professional,[7] join social networks (online health communities) to offer and get support from others,[8] and engage in quantified self-tracking of personal health data.[9] Thus, whereas patients will still expect to meet an expert when they seek a healthcare professional, they will arrive with factual knowledge about their condition as well as knowledge about how it influences their overall life situation. Patients will increasingly expect their personal needs and goals to be the base for a collaborative effort to achieve health outcomes they value, making professional-centered care a thing of the past.[10]

Information and communication technologies (ICTs) are transforming most industries and are pervasive in most people's lives.[11] But in healthcare, these technologies have long been under-designed, under-integrated in services and, as a result, under-used.[12] The reason is not lack of technical solutions or even lack of investments in IT, but organizational and ethical issues.[3,7] Increased patient expectations on health providers to use ICT proficiently and in a collaborative fashion, for example by providing real-time access for patients to their own medical records and to comparative effectiveness data, and to combine this information to personalize care, may change this,[13] and provide an external pressure for change.[14] Concurrently, there is also an internal demand in many healthcare organizations connected to the need to have access to the right information at the right time for the right person in the right format.[14] In sum, whereas the technical ICT solutions and patients' as well as organizational readiness to embrace ICT are in place, innovation in healthcare management and organization is needed to meet current and future societal changes.[7]

Co-care

> *Nowadays I work together with my doctor and the computer for every change in the treatment. I can check my chronic disease at home between visits. Before I go see my doctor, I measure my own health. ... The Internet support system enables me to contribute to the management of my own disease. I can monitor the effects of drugs, how they help me, and if they've failed. I can better understand my doctor's reasoning when we decide on my medication and how I can get the best results.* Patient featured on the Swedish Rheumatology Quality Register website.[15,16]

Co-care, co-production, co-creation and co-design, as well as patient-centered care, collaborative care, shared decision making, patient activation and patient engagement are related constructs that in different ways emphasize that healthcare requires an interaction between patient and caregiver.[6,17–19] Here, *co-care* is used to describe an approach that stresses (1) that the role of healthcare providers is to complement people's own resources to manage their health so that the patient's and healthcare provider's resources are combined to achieve the best possible outcome (i.e. with the proportion of contributions varying depending on patient and condition) and (2) the use of appropriate tools/artifacts (e.g. ICT) to enable creating, shaping, sharing and applying knowledge (i.e. using informatics as defined by Coiera[20]) across these actors.

Viewing artifacts like ICT as an integral part of a process is in line with the theory of distributed cognition (also discussed as distributed intelligence, creativity, knowledge, etc.).[21] In this theory, cognitive activity can be spread between individuals, between individuals

and objects in the environment (artifacts) and across time and space.[22] Following this view, co-care can be defined as a system consisting of (1) the patient and their resources (including their own knowledge and skills as well as relevant social connections, including relatives, caregivers, friends, social networks and the community), (2) the healthcare provider and their resources, (3) ICT as an artifact that allows information to be accessible at the right time and place for the right person and in the right format and (4) the interactions, intentions and abilities of these parties to produce a health outcome that is valued by the patient and endorsed by the healthcare provider. The quote above illustrates how these interactions play out in practice.

This definition of co-care aligns with a conceptual model that recently was developed in a collaboration between the Dartmouth Institute and Karolinska Institutet.[23] In this model, co-care is viewed as a learning health system where the core is partnership for co-production between patients and providers. The partnership is enabled by ICT, using a system architecture that allows processing and communication of feed-forward and feed-back information in a shared information environment. At the individual level, the system offers possibilities for patients and providers to generate, track and share longitudinal data, thereby providing a tool for self-management and individualized evaluation of progress. In addition, the system has a population health application (i.e. health outcomes of a group of individuals[24]) by enabling accumulation of data so that it can be used for research and continuous improvement purposes. Thus, research is made part of the system. In essence, the system bridges individual level data (e.g. electronic medical records and personal health records) and population data (e.g. clinical databases and registries).[25] The model is currently being applied to the transformation of health services for rheumatology and for Parkinson's disease in Stockholm County Council, in a research program involving a research-practice partnership to develop, implement and evaluate co-care in practice.[15] The research builds on previous work with the Swedish rheumatology quality register, which is a feed-forward system where patient-reported data, including outcome measures, is available for both patients and clinicians.[16,25,26] The data are used to support self-management and as a decision support to guide the clinicians in providing the best, personalized care.[16,26] Aggregated data can also be used for local improvements, benchmarking and clinical studies and multicenter comparative studies.[26] In the ongoing research program, existing co-care models and processes are further developed and extended to new groups of patients, providers and ICT solutions with the goal of accumulating learning across applications to develop generic models and tools for co-care. A specific focus is on how these types of service innovations can be spread and implemented in clinical practice, and the preconditions for doing so.[15]

Contributions with co-care

Co-care – along with its siblings (co-production, co-creation, co-design, etc.) – is likely to play a central role in the future of healthcare as it offers an appealing response to the disruptive transformation of healthcare that is needed to meet the demands of today and tomorrow.[27,28] The benefits can be both financial and social. First, it can utilize the human capital that knowledgeable and engaged patients and relatives offer. Second, it acknowledges the interdependency between individuals and healthcare providers in producing better health outcomes, and may thus encourage more effective solutions to health problems. Third, it makes use of ICT where appropriate, possibly reducing the burden on patients and healthcare providers. Fourth, it offers possibilities for evidence-based individualized medicine when data that are accumulated across patients are used to inform clinical decision making by extracting data from pools of patients with similar characteristics.[29] Overall, co-care is a promising driver of disruptive innovation that may radically boost quality, productivity and efficiency.

Implications for healthcare management research and practice

The introduction of co-care models calls for change at multiple levels, including policies, new designs of healthcare services and attitudinal and practice change among providers, healthcare professionals and patients. First, system changes are needed, ranging from the policy level to the organization and management of healthcare, both across and within healthcare provider organizations.[30] Co-care requires that healthcare is organized with the needs of the patient in mind. The traditional way of organizing healthcare along medical disciplines, and the use of production logics inspired by the manufacturing industry, is suboptimal or even detrimental to co-care.[3] As co-care builds on the formation of distributed cognitions, and given that people are not neatly split along the traditional organizational boundaries, new ways of organizing will be needed, including for example integrated care models, medical homes and accountable care organizations. Business models that are better aligned with how value is created through co-care also need to be explored. These are likely to bear more resemblance to value logics that build on linking customers in networks, or possibly on solving problems, than to transforming input into output.[31] AirBnB and Uber are

examples from other fields of how ICT can be utilized to create value through a network logic, whereby the value is determined by the strength and density of the connections between the nodes in the network. In healthcare, PatientsLikeMe and other online health communities create value through network logic.[32,33] Further innovations along these lines will be important in the realization of co-care. For example, there will be a network effect for co-care models built around clinical databases: the more patients and providers that enter data, the more valuable the system will become as the validity of and possibility for comparisons increases.[25]

Also, new steering and reimbursement models that facilitate co-care will be needed. Many of today's steering and reimbursement systems are designed in a way that directly counteracts care providers' capabilities to optimize their care processes to support co-care, for example by not reimbursing self-management education.[6] On the one hand, activity-based pay-for-performance may drive activities that are inconsistent with a co-care process. In co-care, the provider is one part of a system (a distributed cognition) within which cognition, and thus activities and tasks, should be disbursed to the most appropriate part and, thus, may involve patients or ICT performing activities that have traditionally been performed by the healthcare provider. Whereas this is positive from a resource utilization perspective, lowered revenues may discourage healthcare providers from pursuing such changes. On the other hand, if health outcomes are co-produced, what implications does this have for models that reimburse healthcare for the results they produce? Is it possible to include co-care in the estimation of value that a healthcare provider is reimbursed for? Research is needed on reimbursement models that facilitate a system approach to care, involving not only healthcare providers and patients but also ICT.

Overall, system change needs to be designed so that it supports change in (1) healthcare professionals' attitudes and behavior towards engaging in a partnership with patient and technology that will enable the patient and healthcare provider to achieve mutually set goals and (2) the corresponding change in patient attitude and behavior. The experience is that this shift is challenging and that the expert role and professional-driven agenda is deeply rooted among healthcare professionals.[27] Radical changes to the education of healthcare professionals will also be required.[34] Less focus on factual knowledge (when this can be readily accessible in databases) and more focus on pedagogical and communication skills and informatics is one likely implication, in line with the Institute of Medicines educational vision.[34] For patients, moving towards self-management education that stresses problem-solving rather than technical skills may be a way forward.[6]

Concurrently, there will be diversity in how radical the shift in healthcare attitudes and behaviors will be perceived, e.g. between sub-disciplines and different healthcare professions. For example, allied healthcare professionals (e.g. psychologists, physiotherapists, occupational therapists) are often trained to stress that the health outcome will be determined by the quality of the interaction between two experts: one on the condition and the methods available for managing it, and one on the goals, abilities and contextual restraints and possibilities present in the current situation. In addition, there will be differences between patients and conditions that need to be embraced. Thus, the application of co-care will vary due to setting, patient and profession. Therefore, it is essential that the enactment of co-care be carefully studied and described in different contexts.

The antecedents and potential moderators of co-care, and its consequences, are other basic but central questions for research and practice to address, as is the ethical implication of co-care. Although the so called digital divide (the unequal distribution of access and IT-literacy) seem to be narrowing,[24] there is a risk that a co-care healthcare reform would benefit resourceful patients while putting less resourceful patients at a disadvantage, which should be considered when designing systems for co-care. And is there a risk that patients will be blamed for a lack of results? Similarly, there is a risk that care providers will face ethical dilemmas and increased cognitive and emotional demands when they need to simultaneously consider possibly contradictory priorities from patient- and professional- and financial perspectives,[3] such as, on the one hand the drive toward standardization of processes and limiting of unnecessary care and, on the other hand, the trend to increase patient choice.[5,35] How can such risks be mitigated? In addition, there are both legal and ethical considerations related to the ICT component of co-care that needs to be managed, including how sensitive information can be stored, shared and accessed safely and how the authenticity and accuracy of data can be ensured.[7]

Once successful approaches have been identified, the next challenge for healthcare management research and practice is to move from small-scale social innovations to system-wide change. This introduces an implementation challenge, because like all complex social innovations, outcomes are dependent on interactions within a system of actors and artifacts, within a specific context. Thus, we need research on how, once we have identified an improvement, we can enable organizations, managers, professionals and patients to put it into use. This calls for implementation approaches that embrace dynamic and continuous development of what is introduced, as well as for evaluation

frameworks that can uncover effects of these dynamic changes. Moreover, co-care offers exciting opportunities to move our view on evidence-based medicine from what is best for the average patient to what is best for the specific patient (i.e. personalized or individualized medicine). This, in turn, has far-reaching implications for how we translate research evidence into practice, the role of clinical guidelines (that are based on average treatment effectiveness),[29] etc. In all, co-care introduces a shift not only in how knowledge is utilized (e.g. from research (population) to patient and from patient to population) but also in the view of how knowledge is created (through the active engagement of the patient as a partner both in the utilization and production of knowledge) that needs to be explored.

Conclusions

Societal changes will bring about radical changes in healthcare. Co-care takes a system approach to the production of health outcomes, entailing the contributions of and interactions between patient, healthcare provider and ICT. In co-care, knowledge is not attributed to a single entity but is rather distributed between them. By new ways of generating, sharing and consuming information, co-care is situated at the cross-road between big data and personal data, offering exciting opportunities for personalized medicine. To allow this to happen, and thus for co-care to be realized in practice, several challenges will need to be addressed, including how to move from profession-centeredness to patient-centeredness and from viewing care as a transformation of input to a product to viewing care as linking needs and knowledge. It will need to involve attitude and behavior change among patients, healthcare professionals, managers, educators, and decision- and policy-makers. The introduction of co-care also calls for research allowing methodological and theoretical development enabling the accumulation of knowledge, as this is necessary in order to go from successful local innovation to widespread system change.

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References

1. Barnett K, Mercer SW, Norbury M, et al. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet* 2012; 380: 37–43.
2. Berwick DM and Hackbarth AD. Eliminating waste in us health care. *JAMA* 2012; 307: 1513–1516.
3. Moses H, Iii, Matheson DM, et al. The anatomy of health care in the United States. *JAMA* 2013; 310: 1947–1964.
4. Tinetti ME, Fried TR and Boyd CM. Designing health care for the most common chronic condition – multimorbidity. *JAMA* 2012; 307: 2493–2494.
5. Salisbury C. Multimorbidity: redesigning health care for people who use it. *Lancet* 2012; 380: 7–9.
6. Bodenheimer T, Lorig K, Holman H, et al. Patient self-management of chronic disease in primary care. *JAMA* 2002; 288: 2469–2475.
7. Knaup P, Ammenwerth E, Dujat C, et al. Assessing the prognoses on Health Care in the Information Society 2013 – thirteen years after. *J Med Syst* 2014; 38: 1–14.
8. Griffiths F, Cave J, Boardman F, et al. Social networks – the future for health care delivery. *Soc Sci Med* 2012; 75: 2233–2341.
9. Swan M. Emerging patient-driven health care models: an examination of health social networks, consumer personalized medicine and quantified self-tracking. *Int J Environ Res Public Health* 2009; 6: 492–525.
10. Coulter A. Paternalism or partnership?: patients have grown up – and there's no going back. *BMJ* 1999; 319: 719.
11. Haux R, Ammenwerth E, Herzog W, et al. Health care in the information society. A prognosis for the year 2013. *Int J Med Inform* 2002; 66: 3–21.
12. Poon EG, Jha AK, Christino M, et al. Assessing the level of healthcare information technology adoption in the United States: a snapshot. *BMC Med Inform Decis Mak* 2006; 6: 1.

13. Cassel CK and Guest JA. Choosing wisely: helping physicians and patients make smart decisions about their care. *JAMA* 2012; 307: 1801–1802.
14. Moxham C, Chambers N, Girling J, et al. Perspectives on the enablers of e-heath adoption: an international interview study of leading practitioners. *Health Serv Manag Res* 2012; 25: 129–137.
15. Brommels M. *Co-care for people with chronic illness: Developing, implementing and evaluating models of partnership care*. Medical Management Centre at Karolinska institutet: Swedish Research Council for Health, Working Life and Welfare (Forte), 2015.
16. Nelson EC, Eftimovska E, Lind C, et al. Patient reported outcome measures in practice. *BMJ* 2015; 350: g7818.
17. Batalden M, Batalden P, Margolis P, et al. Coproduction of healthcare service. *BMJ Qual Saf* 2015: bmjqs-2015-004315.
18. Coulter A. Patient engagement – what works? *J Ambul Care Manage* 2012; 35: 80–89.
19. Elg M, Engström J, Witell L, et al. Co-creation and learning in health-care service development. *J Serv Manage* 2012; 23: 328–343.
20. Coiera E. *Guide to medical informatics, the internet and telemedicine*. London: Chapman and Hall, 1997.
21. Hutchins E. *Cognition in the wild*. Cambridge MA: MIT press, 1995.
22. Hollan J, Hutchins E and Kirsh D. Distributed cognition: toward a new foundation for human-computer interaction research. *ACM Trans Comput-Hum Interact* 2000; 7: 174–196.
23. Institutet DIK. Preparing to import a successful model for an interactive disease registry system to the United States. *Program Results Report*, Princeton, NJ, Robert Wood Johnson Foundation, 28 February 2015.
24. McDaniel AM, Schutte DL and Keller LO. Consumer health informatics: from genomics to population health. *Nurs Outlook* 2008; 56: 216–223.e3.
25. Ovretveit J, Keller C, Forsberg HH, et al. Continuous innovation: developing and using a clinical database with new technology for patient-centred care – the case of the Swedish quality register for arthritis. *Int J Qual Health care* 2013; 25: 118–124.
26. Hvitfeldt H, Carli C, Nelson EC, et al. Feed forward systems for patient participation and provider support: adoption results from the original US context to Sweden and beyond. *Qual Manage Healthc* 2009; 18: 247–256.
27. Berwick DM. What 'patient-centered' should mean: confessions of an extremist. *Health Aff* 2009; 28: w555–w565.
28. Wasson JH, Forsberg HH, Lindblad S, et al. The medium is the (Health) measure: patient engagement using personal technologies. *J Ambul Care Manage* 2012; 35: 109–117.
29. Basu A, Jena AB, Goldman DP, et al. Heterogeneity in action: the role of passive personalization in comparative effectiveness research. *Health Econ* 2014; 23: 359–373.
30. Gauld R, Burgers J, Dobrow M, et al. Healthcare system performance improvement: a comparison of key policies in seven high-income countries. *J Health Organ Manage* 2014; 28: 2–20.
31. Stabell CB and Fjeldstad ØD. Configuring value for competitive advantage: on chains, shops, and networks. *Strategic Manage J* 1998; 19: 413–437.
32. Wicks P, Massagli M, Frost J, et al. Sharing health data for better outcomes on PatientsLikeMe. *J Med Internet Res* 2010; 12: e19.
33. van der Eijk M, Faber MJ, Aarts JWM, et al. Using online health communities to deliver patient-centered care to people with chronic conditions. *J Med Internet Res* 2013; 15: e115.
34. McBride AB and Detmer DE. Guest editorial: using informatics to go beyond technologic thinking. *Nurs Outlook* 2008; 56: 195–196.
35. Rosenbaum L. The whole ball game – overcoming the blind spots in health care reform. *N Engl J Med* 2013; 368: 959–962.