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Milestones, barriers and beacons: Shared decision making in Canada inches ahead

Meilensteine, Barrieren und Signale: partizipative Entscheidungsfindung in Kanada auf dem langsamen Vormarsch

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ABSTRACT

Canada's approach to shared decision making (SDM) remains as disparate as its healthcare system; a conglomerate of 14 public plans – ten provincial, three territorial and one federal. The healthcare research funding environment has been largely positive for SDM because there was funding for knowledge translation research which also encompassed SDM. The funding climate currently places new emphasis on patient involvement in research and on patient empowerment in healthcare. SDM fields have expanded from primary care to elder care, paediatrics, emergency and critical care medicine, cardiology, nutrition, occupational therapy and workplace rehabilitation. Also, SDM has reached out to embrace other health-related decisions including about home care and social care and has been adapted to Aboriginal decision making needs. Canadian researchers have developed new interprofessional SDM models that are being used worldwide. Professional interest in SDM in Canada is not yet widespread, but there are provincial initiatives in Alberta, British Columbia, Ontario, Quebec and Saskatchewan. Decision aids are routinely used in some areas, for example for prostate cancer in Saskatchewan, and many others are available for online consultation. The Patient Decision Aids Research Group in Ottawa, Ontario maintains an international inventory of decision aids appraised with the International Patient Decision Aid Standards. The Canada Research Chair in SDM and Knowledge Translation in Quebec City maintains a website of SDM training programs available worldwide. These initiatives are positive, but the future of SDM in Canada depends on whether health policies, health professionals and the public culture fully embrace it.

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ZUSAMMENFASSUNG

Kanadas Herangehensweise an die partizipative Entscheidungsfindung (PEF) ist nach wie vor so uneinheitlich, wie sein Gesundheitssystem aufgebaut ist, nämlich als ein Konglomerat aus 14 Teilsystemen: zehn provinzial- und drei territorialstaatliche sowie ein bundesstaatliches. Die Forschungsförderung im Bereich der Gesundheitsforschung ist gegenüber PEF im Großen und Ganzen positiv eingestellt; so wurden Projekte in der Wissenstransferforschung finanziert, worunter auch das Thema PEF fällt. Die Förderschwerpunkte liegen neuerdings auf der Einbeziehung von Patienten in die Forschung und auf dem Patienten-Empowerment im Gesundheitswesen. Der Anwendungsbereich von PEF hat sich ausgehend von der Grundversorgung inzwischen auf Altenbetreuung, Pädiatrie, Notfall- und Intensivmedizin, Kardiologie, Ernährung, Ergotherapie sowie Arbeitsrehabilitation ausgeweitet. Darüber hinaus erstreckt sich PEF mittlerweile auch auf andere gesundheitsbezogene Entscheidungsprozesse, z. B. in Bezug auf häusliche Pflege und Sozialdienste, und ist an die Entscheidungsbedürfnisse der indigenen Bevölkerungsgruppen angepasst worden. Kanadische Wissenschaftler haben neue berufsübergreifende PEF-Modelle entwickelt, die weltweit Anwendung finden. In Kanada ist das Interesse der einschlägigen Berufsgruppen an PEF zwar noch nicht besonders weit verbreitet, doch gibt es in den Provinzen Alberta, British Columbia, Ontario, Quebec und Saskatchewan verschiedene PEF-Initiativen. In einigen Bereichen kommen routinemäßig Entscheidungshilfen für Patienten zum Einsatz, in Saskatchewan beispielsweise bei Prostatakrebs, und viele weitere solcher Entscheidungshilfen stehen im Rahmen von Online-Konsultationen zur Verfügung. Die *Patient Decision Aids Research Group* in Ottawa (Ontario) pflegt ein internationales Register von Entscheidungshilfen, die nach den Kriterien der International Patient Decision Aids Standards (IPDAS) Collaboration bewertet wurden. Der kanadische Forschungslehrstuhl für PEF und Wissenstransfer in Quebec City unterhält eine Webseite zu international verfügbaren PEF-Schulungsprogrammen. Diese Initiativen sind positiv zu bewerten, doch wird die Zukunft von PEF in Kanada davon abhängen, ob sich Gesundheitspolitiker, Ärzte und die Öffentlichkeit uneingeschränkt zu PEF bekennen.

Healthcare in Canada

Canada's healthcare system is a combination of 14 publicly funded plans – ten provincial, three territorial, and one federal – covering the provision of most hospital and medical services for a population of more than 35 million people. These plans share a set of principles specified in the federal *Canada Health Act* of 1984 and are funded through taxes and to a limited extent, user or employer contributions. The federal government contributes to the funding of provincial and territorial health plans, subject to strict conditions and constraints. The provinces are required to provide first-dollar coverage for all medically necessary hospital and medical services and must oversee and manage the healthcare system in order to receive federal transfer funds.

Political climate

The Conservative government that held office in Canada from 2006 to 2015 did not perceive healthcare as a core federal responsibility. While it continued to fund provincial health programs at a high level, including a 6% annual increase in heath transfer funds, its implicit policy was to let provinces determine their own delivery models, structure, and administration, as long as they did not contradict *The Canada Health Act*. This approach encouraged innovation and some provinces were able to introduce major reforms in funding, access, and governance. The downside was an even more fragmented health system, with each province or territory pursuing its own vision and a declining interest in nation-wide programs [1,2].

It is too early to tell what the current Liberal federal government, which took office in 2015, will achieve. Currently, the focus seems to be on reducing federal funding, even if it means abandoning attempts to maintain a national consensus on health policy. In 2016-2017, the federal government reached separate agreements on healthcare funding levels with all territories and all but one province in exchange for predictability and investments in a few priority areas including mental health, addictions, and care of the elderly. No one knows what the future will look like, other than predictable reduced funding levels. In addition, the federal budget released in March 2017 offered no increase in health research funding for the cash-strapped *Canadian Institutes of Health Research (CIHR)*, Canada's main public funder of health research [3].

In Canada, the dissemination and scaling up of policy innovations once followed a predictable pattern. A successful initiative in one province led to the federal government extending the measure to the whole country using a combination of fiscal and convening power with no guarantee that it would be successful. Indeed, Canada has often been referred to as a "country of perpetual pilot studies" with little success in major scaling up of evidence-based practices across its multiple jurisdictions [4]. Canada's health system itself came into existence following two insurance reforms in one province. Yet it is difficult to see how this could happen again in the current context. New pathways need to be developed, using knowledge and policy networks that transcend provincial and territorial borders.

Obstacles to public engagement and scaling-up of shared decision making

A further obstacle to the dissemination of innovations, particularly through public engagement, resides in the abolition of regional health structures by most provinces over the last decade, e.g., Alberta in 2008, Quebec in 2016 and Saskatchewan in 2017. Starting in the 1990s, most provinces established regional health authorities, ranging from the limited functions of the Ontario regional health planning organisations to the vast responsibilities of Alberta's and Manitoba's integrated health regions. Health regions were created with citizen engagement and control in mind and usually included participatory mechanisms such as public boards or citizen assemblies. They also served as a relay between health innovators and provincial public authorities, facilitating the scaling up of successful local initiatives. The disappearance of regional authorities may not only affect the democratic culture of existing healthcare structures – the citizen's voice being de facto muted – but also affect the system's capacity to benefit from experiments conducted at local levels, such as those involving shared decision making (SDM). Other policies at the provincial level have differing impacts on public participation in healthcare decisions.