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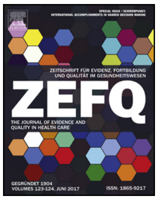

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The long way of implementing patient-centered care and shared decision making in Germany

Der lange Weg zur Implementierung patientenzentrierter Versorgung und partizipativer Entscheidungsfindung in Deutschland

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ABSTRACT

The main focus of the paper is on the description of the development and current state of research and implementation of patient-centered care (PCC) and shared decision making (SDM) after fifteen years of substantial advances in health policy and health services research.

What is the current state of SDM in health policy?
The "*Patients' Rights Act*" from 2013 standardizes all rights and responsibilities within the framework of medical treatment for German citizens and legal residents. This comprises the right to informed decisions, comprehensive and comprehensible information for patients, and decisions based on a clinician-patient-partnership.

What is the current state of SDM interventions and patient decision support tools?
SDM training programs for healthcare professionals have been developed. Their implementation in medical schools has been successful. Several decision support tools – primarily with support from health insurance funds and other public agencies – are to be implemented in routine care, specifically for national cancer screening programs.

What is the current state of research and routine implementation?
The German government and other public institutions are constantly funding research programs in which patient-centered care and shared decision-making are important topics. The development and implementation of decision tools for patients and professionals as well as the implementation of CME trainings for healthcare professionals require future efforts.

What does the future look like?
With the support of health policy and scientific evidence, transfer of PCC and SDM to practice is regarded as meaningful. Research can help to assess barriers, facilitators, and needs, and subsequently to develop and evaluate corresponding strategies to successfully implement PCC and SDM in routine care, which remains challenging.

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ZUSAMMENFASSUNG

Hauptfokus des Beitrags ist die Darstellung der Entwicklung und des derzeitigen Standes bezüglich Implementierung und Beforschung einer patientenzentrierten Versorgung und der partizipativen Entscheidungsfindung (PEF) nach 15 Jahren substanzieller Fortschritte in der Gesundheitspolitik und Versorgungsforschung in diesem Bereich.

Welchen Stand hat PEF in der Gesundheitspolitik?

Das Gesetz für Patientenrechte von 2013 regelt alle Rechte und Verantwortlichkeiten bezüglich medizinischer Behandlungsmaßnahmen für deutsche Bürger und legale Einwohner. Es umfasst sowohl das Recht auf informierte Entscheidungen, verständliche Informationen und die Vermittlung an Patienten als auch medizinische Entscheidungen, die partnerschaftlich von Ärzten (und anderen Gesundheitsberufen) und Patienten getroffen werden.

Wie steht es mit PEF-Interventionen und Instrumenten zur Unterstützung von Patientenentscheidungen?

Spezifische Trainingsprogramme zur partizipativen Entscheidungsfindung für medizinische Fachkräfte wurden entwickelt und erfolgreich in der medizinischen Ausbildung implementiert. Einige medizinische Entscheidungshilfen wurden - hauptsächlich mit Unterstützung von Krankenkassen oder im Auftrag öffentlicher Institutionen - erstellt und befinden sich derzeit in der Implementierung, insbesondere für die nationalen Screeningverfahren für Krebserkrankungen.

Wie ist der aktuelle Stand der Forschung? Wie steht es mit der routinemäßigen Umsetzung?

Die Bundesregierung und andere öffentliche Träger fördern konstant Forschungsprogramme, in denen Patientenorientierung und PEF einen Schwerpunkt bilden. Es sind jedoch verstärkte Anstrengungen im Bereich der Entwicklung und Implementierung von Entscheidungshilfen für Patienten sowie der Implementierung von Trainingsprogrammen für Fachkräfte notwendig.

Wie sieht die Zukunft aus?

Mit der Unterstützung der Gesundheitspolitik und gestärkt durch wissenschaftliche Belege wird der Transfer einer patientenzentrierten Versorgung und einer partizipativen Entscheidungsfindung in das deutsche Versorgungssystem als bedeutsam eingeschätzt. Forschung kann dabei unterstützen, Barrieren, förderliche Bedingungen und Bedarfe zu erfassen. Daraus können Strategien entwickelt werden, um die Übertragung in die Routineversorgung zu evaluieren. Dies bleibt eine Herausforderung für die Zukunft.

Introduction

A fundamental aspect of the German health care system is the sharing of responsibility and decision-making powers between the federal government, the regional state governments, and civil society organizations. The federal and regional governments delegate power to the self-regulated organizations of payers and providers. Health care coverage is universal and mandatory for all citizens and permanent residents. The statutory health insurance (SHI) system is mainly financed through uniform contribution rates paid jointly by employers and employees. The benefit packages of the SHI funds are fundamentally equal and defined by law. While the SHI covers approximately 86% of the population, 11% are insured through substitutive private health insurance (PHI). PHI is financed through risk-related premiums, and while the basic benefit package is similar to the SHI package, there exist options according to the needs of the insured person.

Patient-centered care and patient involvement on the *macro level*

The *Federal Joint Committee* (*Gemeinsamer Bundesausschuss, G-BA*) is the highest legal entity under public law. Its main task is to decide which medical procedures are adequate, practicable and cost-effective. Around 220 permanent and topic-specific *patient representatives* are official members within the committee with *advisory and proposal* rights, but still no voting rights. Furthermore, the Federal "*Commissioner for Patients and for Nursing of the Federal Government*" represents patients' interests and rights within the health care system. To foster patient-centered care (PCC) and innovative health care delivery the Joint Committee founded the "Innovation Committee" (*Innovationsausschuss*) in 2015, which is responsible for an annual investment of 300 Mio. € (2016-2020). The "*Law on Patients' Rights*" (*Patientenrechtegesetz*) from 2013 standardizes all rights and responsibilities within the framework of medical treatment, e.g. the right for comprehensive and understandable patient information, and informed decisions based on a respectful clinician-patient-partnership.

The *National Cancer Plan* (NCP) is an initiative, led by the *Federal Ministry of Health* since 2008, to coordinate and improve cancer care. Besides its goals to improve early detection, treatment delivery structures, and efficient treatment regimen, the plan aims fostering PCC through 1) improving the quality of patient information, 2) involving patients actively in making decisions regarding their care and 3) implementing SDM in clinical practice. The "*Law on the Further Development of the Early Detection of Cancer and Quality Assurance*" turns the current cancer screening into population-based quality assured programs in accordance with European guidelines [1]. Special emphasis is put on the provision of balanced and unbiased information on benefits and harms of the different screening procedures. Thus, German health policy is taking a clear stance against pushing utilization rates uncritically. This position is a paradigm shift to informed choice of fundamental importance.

Patient-centered care and patient engagement on the *meso level*

The *Institute for Quality and Efficiency in Health Care* (IQWiG) is an independent, non-governmental and non-profit foundation intended to establish evidence-based reports on medical interventions, methods for screening and diagnosis, treatment guidelines, etc. In addition, as an independent publisher, IQWiG is providing *evidence-based health information* for patients and the general community supporting evidence-based decision-making. The website "*gesundheitsinformation.de*" has covered more than 150 important medical topics so far. In addition, the IQWiG has developed three *decision aids* for the national breast, colon, and cervical cancer screening programmes commissioned by the G-BA (table 1). Finally, the institute was recently commissioned by the Federal