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The status of shared decision making and citizen participation in Israeli medicine

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Summary

What about policy regarding SDM?

Though informed consent and patients' right to information are regulated by Israeli law, there is a low level of formal activities focused on shared decision making (SDM) in Israel. Further, there are few organized programs to promote SDM among medical professionals or the public, and governmental support of SDM-related research is minimal.

What about tools – decision support for patients?

The Israeli government does not have a program on development of patient decision aids.

What about professional interest and implementation?

Nonetheless, patients have begun to influence litigation in both formal and informal capacities, medical schools have begun to incorporate

courses for improving physician-patient communication into their curricula, and the largest national health plan has initiated a plan to increase public awareness. Funding for researching and promoting SDM is not centrally allocated, and studies show that despite the positive effects of SDM, such an approach is infrequently applied in actual clinical practice, and initiatives to promote SDM (e.g., decision aids) are in their infancy.

What does the future look like?

In conclusion, though not actively promoting SDM at present, Israel, with its governmentally regulated universal coverage with good access to high-level services possesses all the requisite elements for rapid, widespread advances in SDM in future years.

Key words: Shared decision making, Israel, patient autonomy, informed consent, health care system, patient participation
(As supplied by publisher)

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Partizipative Entscheidungsfindung und Bürgerbeteiligung im israelischen Gesundheitswesen: eine Bestandsaufnahme

Zusammenfassung

Wie steht es mit gesetzlichen Regelungen zur PEF?

Obwohl *Informed Consent* (Einwilligung nach Aufklärung) und das Recht des Patienten auf Aufklärung in Israel gesetzlich geregelt sind, gibt es kaum offizielle Aktivitäten, in deren Zentrum die Partizipative Entscheidungsfindung (PEF) steht. Zudem existieren nur wenige organisierte Programme zur Förderung von PEF in der Ärzteschaft oder in der Öffentlichkeit, und auch die staatliche Unterstützung für PEF-bezogene Forschung ist gering.

Wie steht es mit PEF-Instrumenten – Entscheidungshilfen für Patienten?

Die israelische Regierung unterhält kein Programm zur Entwicklung von Entscheidungshilfen für Patienten.

Wie steht es mit dem Interesse der Profession und der Implementierung?

Nichtsdestotrotz haben Patienten begonnen, sowohl formal als auch informell Einfluss auf die Rechtsprechung zu nehmen. Medizinische

Hochschulen gehen zunehmend dazu über, Kurse zur Verbesserung der Arzt-Patient-Kommunikation in ihre Lehrpläne aufzunehmen, und der größte nationale Gesundheitsplan hat eine Initiative zur Steigerung des öffentlichen Bewusstseins für diesen Problembereich gestartet. Finanzielle Mittel für die Beforschung und Förderung von PEF werden nicht zentral zugewiesen, und Studien zeigen, dass die PEF trotz ihrer positiven Wirkungen im klinischen Alltag tatsächlich nur sehr selten zur Anwendung kommt. Initiativen zur Förderung von PEF (z.B. Entscheidungshilfen) stecken noch in den Kinderschuhen.

Wie sieht die Zukunft aus?

Auch wenn PEF gegenwärtig nicht aktiv gefördert wird, so besitzt Israel aufgrund seines staatlich regulierten allgemeinen Krankenversicherungsschutzes mit einem guten Zugang zu hochwertigen Gesundheitsleistungen doch alle nötigen Voraussetzungen, um PEF in zukünftigen Jahren rasch und auf breiter Basis voranzutreiben.

Schlüsselwörter: Partizipative Entscheidungsfindung, Israel, Patientenautonomie, Informed Consent (Einwilligung nach Aufklärung), Gesundheitssystem, Patientenbeteiligung

(Wie vom Gastherausgeber eingereicht)

Background on the Israeli health care system

Israel has a national health insurance system that provides high-level universal coverage.¹ The system is mostly publicly funded (58% vs. 42% private financing [2]), comprising about 8% of the gross domestic product (GDP; see Box 1). A recent national survey revealed that 89% of respondents were satisfied with the professionalism of primary care physicians (PCPs) and 86% with the professionalism of specialists. 93% were satisfied with the interpersonal skills of PCPs and 93% with the interpersonal skills of nurses [3].

¹Prior to the enactment of national health insurance in 1995, approximately 4% of the population – about 200 000 people – were uninsured. Uninsured rates were highest among the Arab population (12%), residents of the northern region (10%) and people aged 15 to 34 (8%). These percentages are comparatively low; in the United States, for example, over 15% of the population are uninsured [1].

Efforts to promote SDM in Israeli legislation and in the healthcare system

Patient involvement in their own care

Though there is no direct, explicit treatment of SDM in Israeli law, the requisite conditions are encapsulated in the Patients' Rights Law of 1996.

Patients' Rights Law

The *Patients' Rights Law* was enacted in 1996 and emphasizes that patient rights go beyond health care alone. Most pertinent to SDM are the patient's right to a second opinion, to informed consent to medical treatment, and to access to personal medical information [4]. Patients may refuse treatment, yet if a patient is in grave danger, the clinician may still administer the required treatment, pending *Ethics Committee* approval. Similarly, pending *Ethics Committee* approval, the clinician may decline to disclose medical information if doing so might be harmful or life-threatening to the patient. Subsequent to the enactment of the Patients' Rights Law, the *Society for Patients' Rights* educated the public

regarding patients' rights [4] and informed consent [5].

The Dying Patient Act

The *Dying Patient Act* of 2005 stipulates that decisions concerning dying patients consider the patient's wishes in addition to the medical condition and degree of suffering. The patient's wishes are to be periodically reassessed, and if the patient is not competent at the time of the decision, the physician is to rely upon the patient's previously expressed wishes, either directly or from testimonies of close friends and family. The Israeli Parliament is soon to consider a November 2010 bill, modeled upon the Oregon Death with Dignity Act, which would amend the Act to legalize the prescription of lethal drugs to a dying patient upon the patient's request [6].

Patient involvement in health policy

Public involvement in Israeli health policy has included a variety of formal and informal activities, programs and discussions [7].

Box 1: The State of Israel: Demographics and Health Care Spending

In September 2010, the State of Israel had an estimated population of 7.6 million, of whom 75% were Jewish and 20% were Arab [1]. Israel is a relatively young society, with 28% of the population under 15 years old (compared with 17% in other Western countries) and only 10% (compared with 15%) over 64 years. Life expectancy in 2009 was 79.7 years for men and 83.5 years for women, an increase from the previous year of 0.7 and 0.5 years, respectively. Infant mortality rate in Israel has been dropping and was estimated at 3.8 per 1000 live births in 2009. As of 2008 cancer was the leading cause of death (26%), followed by heart disease (17%). National spending on healthcare was estimated at 60.6 billion New Israeli Shekels in 2009, approximately 8% of the GDP, an increase of 4% from the previous year. However, compared with Israel, 23 member countries of the Organisation for Economic Co-operation and Development (OECD) spent a larger percentage of their GDP on healthcare.

Formal Involvement

Israeli citizens serve on the boards of the national health plans and as members of the *National Health Council*, a nationally representative advisory body to the *Ministry of Health*. Citizens are also included in the Ministry's ad hoc committees on such sensitive policy issues as fertility and procreation and electronic medical records [8,9].

The public committee to revise the standard 'basket' of health services to which every Israeli citizen is legally entitled is comprised of representatives from the government, the national health plans, and the public. Approximately 25% of its members have been citizens with no medical background [10,11]. To date, the committee's recommendations, though not legally binding, have been fully adopted.

In 2003 Israel inaugurated the "*Health Parliament*" to involve over 100 citizens from diverse segments of the population in a deliberative process regarding allocation of public funds for healthcare services [12]. Summaries of the proceedings and recommendations of the Health Parliament were presented to the Minister of Health and senior healthcare decision makers. The initiative was discontinued the following year due to funding problems [13].

Informal Involvement

Approximately fifty patient advocacy groups operate in Israel, some linked to specific diseases. Members appear at public legal proceedings and are involved in lobbying against government policies that conflict with patient

interests. Groups are coordinated by the *Israeli Health Consumers' Organization* (Z.V.I.) [7] and by a coalition formed by The Society for Patients' Rights in 2008.

SDM in Israeli medical training and the national health plans

Deans of all four Israeli medical schools indicated that there were no organized programs to promote SDM at their medical schools or affiliated hospitals. However, courses for improving physician-patient communication have been developed and included in the curricula of most medical schools. At *Tel Aviv University*, patient empowerment is taught in formal courses on professionalism and ethics and in simulated role-playing; it is also incorporated into a new 'physician charter' adopted by the Faculty of Medicine. At the *Hebrew University*, the genetic counseling program offers a course on the psychological aspects of decision making (developed and taught by the first author) in which future counselors adopt the perspective of a counselee. Medical students and physicians may also participate in workshops designed to improve physician-patient communication skills offered by the *Israel Center for Medical Simulation* (MSR) [14].

Key personnel affiliated with the four national health plans in Israel indicated that there were no organized programs to promote SDM among their healthcare providers. However, the largest health plan inaugurated a national "Ask

Me 3" program to create patient awareness and reinforce principles of clear health communication [15,16].

Research agenda on SDM

In June 1995 the National Health Council designated the *Israel National Institute for Health Policy and Health Services Research* (NIHP) to oversee implementation of the national health insurance system, conduct relevant research, including surveys, and procure expert professional opinion [17]. Of the 396 NIHP-funded research studies between 1998 and 2010, only 3% were related to SDM (see Box 2), an indication of the relative importance of SDM to Israeli health policy. Indeed NIHP has no funds earmarked for researching and promoting SDM in Israel or developing patient decision aids. Further, there have been no efforts to standardize information communicated to patients on the risks and benefits associated with screening and treatment options [18].

Studies of SDM in Israel

In this section, we briefly review published studies that have investigated SDM in Israel. As not all studies indicated funding from NIHP, these studies are distinct from those discussed in the previous section and listed in Box 2. The studies provide important insights into the factors surrounding sensibilities and issues related to SDM in Israel and thus serve as a context for the development of suitable and effective interventions.

Box 2: Studies Related to Shared Decision Making (SDM) Funded by the Israel National Institute for Health Policy and Health Services Research (NIHP) from 1998-2010.

A sociologic-juristic analysis of the right for participation – viewpoints of minors with life threatening disease
 Factors affecting the decision to immunize against influenza among Israeli workers
 Health above all? The public's perception of the government's role and health insurance issues
 Prenatal technology decision making in the era of information and uncertainty
 Value of information in the decision making process in the healthcare environment
 Genetic counseling in hereditary breast/ovarian cancer in Israel: Psychosocial impact, retention of genetic information, subsequent use of health care services, and consumer satisfaction
 Evaluation of the factors influencing the use of health services (compliance, screening, and treatment) among ultra orthodox breast cancer patients
 Public consultation on priorities in the basket of services under the national health insurance law – values, views and venue
 From compliance to alliance: Engaging psychiatric patients in illness management
 The relationship between the public's perceptions and attitudes towards prevention and early detection of cancer (breast, prostate, colon, skin) and messages in formal health services educational efforts
 The effect of patients' participation in improving the care for diabetes mellitus: A randomized trial in the primary care setting in two regions in Israel

Physician Advocacy of SDM

In a study by Werner et al., 141 Israeli PCPs were presented with one of two vignettes describing a hypothetical clinical encounter involving a calm and cooperative or agitated and uncooperative Alzheimer's disease patient and her caregiver [19]. PCPs indicated that they would question, inform, and involve the caregiver to a greater extent and more consistently than the patient, particularly when the patient was agitated. Eighty-nine percent of PCPs stated that they would reach a decision together with the family, 6% stated they would decide paternalistically, and less than 5% stated they would let the family decide autonomously.

SDM is greatly facilitated by the accessibility of information on the internet, such that physicians may no longer be the primary keepers of medical information. In a representative sample of 118 Israeli PCPs, most physicians (82%) agreed that patient internet use indicates patient involvement and accountability for their medical care, yet 34% felt that the patient or family should rely solely on the physician [20].

Patient Advocacy of SDM

A locally representative sample of hospitalized and ambulatory patients ranked six issues in terms of priority for improvement [21]. Obtaining more information from the physician and participating in decisions² was ranked most desirable (40% of patients ranked it as first or second priority). Easier access to specialists or hospital services was ranked next highest (38% of patients ranking it as top or second priority). The authors suggest that this finding may be related to the desire for greater patient autonomy relative to the paternalistic role of the PCP imposed by the national health plans.

Brezis and colleagues asked Israeli hospitalized patients undergoing surgery or invasive procedures about the quality of their informed consent [22]. Though 98% of patients recalled having signed an informed consent, only 39 to 60% of patients recalled receiving explanations about risks of procedures, and 8 to

40% remembered a discussion about alternative management options. Regardless, overall satisfaction with the decision making process was rated as good or very good by 80% of patients and did not correlate with recall of information. Brezis et al. also asked 496 of the hospitalized patients and 350 Israeli ambulatory patients to indicate their preference for an autonomous, paternalistic, or shared decision-making process [22]. In both settings, approximately 60% of patients preferred SDM, 20% autonomous decision making, and the remainder paternalistic decision making.³ SDM involves not only physician and patient, but also close family members who may be significantly affected by the consequences of medical decisions.⁴ Gilbar and Gilbar evaluated the views of 57 breast cancer patients and their husbands on decision making and physician-patient relationships three to twelve months

²As participants in the Schattner et al. study [21] rated additional information and greater involvement in decision making as a *single item*, patient preferences for improvement in each of these aspects separately cannot be determined.

³These findings are in agreement with those of Coulter and Magee in European patients, of whom 51% favored SDM, 23% autonomous, and the remainder paternalistic decision making [23].

⁴Though Israeli law (as in the UK) requires only that the physician involve the patient; no provision is made for close family [24].

after diagnosis [25]. Patients were under treatment at an oncology clinic in northern Israel. Ninety-three percent of patients felt it was important for them to autonomously make medical decisions. Eighty-nine percent of patients felt it important that the treatment decision be in accord with their spouse's decision, second only to agreement with their own decision and the physician's (both 95%), thereby indicating patients' preference for SDM, in which physician, patient, and spouse are involved. Interestingly, most patients (88%) and spouses (82%) preferred the final decision to be made by the physician, possibly reflecting an aversion to the burden borne by the decision maker, even at the cost of reduced autonomy.

In another study, a nationally representative random sample of Israelis reported their perception of patient participation in the four national health plans [26]. Patients did not feel that they were part of the decision-making process in their health plans. Moreover, perception of patient participation was positively correlated with perception of health plan performance.

SDM in End-of-Life Care

Physicians ($n = 339$) and a random sample of elderly Israelis ($n = 987$) expressed incongruous views on life-sustaining treatment in terminal illness. Specifically, physicians would order significantly more life-sustaining treatments than patients would want or than they would order for themselves in the same position. These incongruities may be attributable to cultural norms underlying Israeli medical practice and may be ameliorated by promoting open communication between physicians and patients in medical education [27].

SDM in Actual Clinical Practice

In a qualitative study, Karnieli-Miller and Eisikovits evaluated whether strategies used by seventeen pediatric gastroenterologists in northern Israel to inform adolescents and their families of a diagnosis of irritable bowel syndrome (IBS) and discuss treatment options were characterized by shared or

paternalistic decision making [28]. In pre-encounter interviews, physicians independently included SDM principles in describing their routine practice. However, observation of the clinical encounters revealed tactics used by physicians to persuade patients to agree with their preferred treatment choice that ultimately reduced patient-physician trust and resulted in low compliance. Additional evidence for the lack of SDM in actual clinical practice comes from an analysis of patient encounters with Israeli PCPs that revealed conflicts in 40% of the consultations, 21% related to rationing of health care resources [29]. PCPs most commonly dealt with resource rationing by withholding other treatment options from their patients. Moreover, opening and closing phases of the encounter were shorter for encounters with conflict, suggesting that more extensive deliberation characterizing SDM may be associated with reduced conflict.

Initiatives to Promote SDM

Segal and Shahar described the design and initial implementation of PANDEX – a web-based application incorporating decision-analytic methods to assist patients and care providers to reach optimal deliberative decisions [30]. In a pre-clinical feasibility study, Israeli genetic consultants were presented with scenarios of women who had come for genetic consultation. Consultants tended to agree with the strategies recommended by PANDEX and acknowledged its capability to provide important insight. Though consultants did feel that PANDEX could serve as a useful tool for patients prior to their meeting with the genetic consultant, they expressed reservations about the integration of a PANDEX-like decision support system in medical care.

Conclusions

This review indicates that Israel possesses the requisite legislative and research infrastructure to facilitate informed patients who are active participants in decisions pertaining to their

health. Indeed, Israel's universal coverage and small number of health plans make rapid, widespread advances in SDM feasible. Burgeoning initiatives to promote SDM in medical training and practice reflect a growing interest in patient involvement. Only by cultivating these initiatives and with continued support for SDM at multiple levels can efforts to promote SDM be advanced, ultimately resulting in a greater role for citizens in their healthcare and health outcomes.

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