

Patient Involvement in the Design and Policy in Healthcare: Highlights from the 4th Annual Conference on Therapeutic Patient Education in Diabetes OTZMA, 21 March 2018

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The 4th Annual Conference on Therapeutic Patient Education in Diabetes was held at the Daniel Hotel in Herzliya, Israel, on 21 March 2018. The focus of the conference was to raise awareness of the expanding trend of patient involvement in the design and policy in healthcare [1].

Over the last 2 decades healthcare has gone from a patriarchal conception, in which the healthcare provider dictates treatment approaches to disease, to a more patient-centered approach in which there is a partnership between the patient and healthcare provider in determining a treatment plan. As a result, patients and their families are becoming more involved and active also within the policy-making processes in healthcare systems [2].

The conference was organized by the OTZMA Diabetes Care Initiative. Clinicians, healthcare providers, and patients from transverse health systems attended the conference, which focused on patient involvement in various processes within the healthcare system. Participants presented specific activities regarding the design of services and policy changes, which occur in other countries or in Israel.

PATIENT INVOLVEMENT: RESEARCH AND THE HEALTHCARE SYSTEM

Chairman of the conference, Prof. Avi Karasik, president of the Israel Endocrine Society, highlighted the importance of more patient involvement in research and the healthcare system, recognizing that presenting the service to the recipients, who are patients and their families, at the planning stage will lead to better patient services and health outcomes and will lower the

economic burden [3,4]. Karasik emphasized that the process of implementing patient involvement within the Israeli healthcare system is slow and that the time has come to adapt and learn from other countries that have already integrated patient involvement within their national health system [3-5].

England is an example of a country that has instituted patient involvement within health policy initiatives. In April 2017, the United Kingdom National Health System (NHS), published an official updated version of their Patient and Public Participation Policy, which was designed to strengthen patient and public interest in the NHS [3]. The British health system recognizes patients and the public. This group includes everyone who uses services, who may do so in the future, or who is strengthening their participation in various aspects of making health policy.

The patients and public are involved at all levels, including commissioning processes and decisions like planning, buying, and monitoring services. They are also involved in the ongoing work of various committees and working groups related to health policy and research in health.

PATIENT INVOLVEMENT: BMJ PATIENT PARTNERSHIP PROGRAM

Dr. Tessa Richards, senior editor at the *British Medical Journal* (*BMJ*) and leader of the *BMJ* patient partnership initiative, presented the *BMJ* patient partnership program, which began about 4 years earlier with the implementation of an innovative strategy called “Walking the Talk” [6]. Within the program, an international patient advisory panel was established to develop a plan to promote patient partnership. The *BMJ* aspired to advance a change in healthcare systems. Richards discussed the reasons for this move and how the strategy was developed including its evolution and attempts to spread this initiative across the 70 journals of the *BMJ* group and beyond. For example, authors of research papers have been asked to state whether and how they involved patients when choosing their research questions, study designs, and outcome measures, as well as how they implemented and disseminated study results.

Richards also stated that the research ecosystem is prepared to consider clinical research papers only if the authors can demonstrate a partnership with the patients in their study. Finally, Richards presented the role of patients on the editorial board, editorial staff, and journal events and campaigns. She noted that specific challenges included editorial collaboration, the need for patient guidance and support, and the value of considering the actions of patients, caregivers, and advocates.

In Israel, the medical field is seeing the first signs of activity and involvement from patients and their families within policy making processes, research initiatives, and healthcare education programs.

PATIENT INVOLVEMENT: DEVELOPMENT OF RESEARCH AND EVALUATION TOOLS

Prof. Orly Manor, chairman of the board of the Israel National Institute for Health Policy Research, and former head of the Israel National Program for Quality Measures in Community Healthcare, presented the growing role of patients in developing research and evaluation tools, as it is reflected in the development of quality indicators and Patient-Reported Outcome Measures (PROMs) [7,8]. The National Program for Quality Measures in Community Healthcare, in cooperation with the four Israeli health maintenance organizations, initiated a study to develop PROMs for patients with diabetes. The process of determining the PROMs was conducted in collaboration with patient focus groups, expert groups, and consultations with an international diabetes consortia for health outcome measurements. Three patient focus groups were conducted, including one with Arabic speaking patients. The participants identified areas that were important to them. These topics included physical functioning, reduction of symptoms (e.g., abdominal pain, dizziness, tiredness, sleepiness, weakness, dry mouth, leg numbness), mental state, and reduction of hypoglycemia. An emphasis was also placed on the ability to manage therapy and self-efficacy. For patients, important factors of treatment successes included having interdisciplinary treatment in one place and at the same visit, receiving information about the disease and treatments available, hosting patient support groups, maintaining a permanent framework for care, initiating routine follow-up care, and demonstrating care and empathy. Findings from patient focus groups, local experts, and international diabetes consortia were included in the selection and construction of PROMs questionnaires for diabetes and, together with the quality indicators, provided a comprehensive picture of the treatment of diabetes in Israel.

PATIENT INVOLVEMENT: POLICY MAKING

Naama Ron, a representative of the Ministry of Health, explained the public involvement in policy making within the ministry. Between 2016 and 2017, the Strategic and Financial Planning Administration, in cooperation with the Medical

Administration of the Ministry of Health, initiated a meeting with the public to investigate the gap between extensive knowledge and advanced technologies compared to the achievements of the Israeli healthcare system in these fields. This gap is reflected in the rising rate of those presenting with chronic illness who have difficulty adhering to treatment and therefore endure unnecessary health deterioration and hospitalization. The basis for this initiative is to understand that the public has the knowledge and experience to approach chronic disease treatment. The main theme that emerged from this process was that both patients and healthcare providers need better ongoing communication based on trust, transparency, and partnership.

PATIENT INVOLVEMENT: ADVOCACY ORGANIZATIONS

Giora Sherf, the general manager of the chronic myeloid leukemia (CML) patient organization (a non-governmental organization), presented the patient's perspective. Sherf represented patient advocacy groups and spoke about local and international initiatives that are led by patients presenting with CML and chronic lymphocytic leukemia (CLL). One of the patient-driven initiatives [9] is one of the most comprehensive studies conducted to date. The study showed factors that influence non-adherence in CML. The unique study involved 2546 patients from 63 countries who completed a patient-driven survey on ways to improve adherence, including dissemination of information about the disease and medication, management of side effects, and support from hematologists. Sherf highlighted many of the important roles that patient advocacy groups have, including support and empowerment of patients, advocacy, and support of advancement in research and therapy. This increased patient involvement, according to Sherf, will lead to a better diagnosis and prognosis, more effective clinical trial participation, further access to therapies, and better optimization of treatment selection.

PATIENT INVOLVEMENT: DEVELOPMENT OF TRAINING PROGRAMS

Dr. Karen Hershkop, head of the Diabetes Education Program at the OTZMA Diabetes Care Initiative, focused on patient involvement in developing training programs with specific emphasis on the diabetes educators program in Israel. While developing this program, focus groups of patients and healthcare providers were involved to define the role of diabetes educators as well as to understand the requirements necessary for their training. Follow-up interviews 1 to 3 years post-training were conducted. All participants noted that the training program was of added value to practitioners in the diabetes field and 81% felt that the program contributes to their daily professional work (publication in process). Having the patient participate in the teaching process started in 1903, when Sir William Osler addressed the New York Academy of Medicine saying, "In what may be called the natural method of teaching,

the student begins with the patient, continues with the patient and ends his study with the patient, using books and lectures as tools, as means to an end. For the junior student ... it is a safe rule to have no teaching without a patient for the text, and the best teaching is that taught by the patient himself” [10].

One example of having patients be involved in the design of a study regarding treatment of diabetes is implemented by the newly established virtual clinic at the Sheba Medical Center.

PATIENT INVOLVEMENT: DESIGN OF A NEW HEALTHCARE SERVICE

With the number of people diagnosed with type 1 diabetes continuously growing, it is necessary that patients receive undivided attention and high-quality care. Dr. Orly Tamir, the director of OTZMA Diabetes Care Initiative and the Israeli Center for Research and Policy in Diabetes at the Gertner Institute for Epidemiology and Health Policy Research, presented the need for a virtual clinic for adult type 1 diabetes patients. Tamir described the unique needs of young adults who are dealing with type 1 diabetes and the shortfalls in the current provision of care for this patient population. Many believe that a virtual clinic would provide a great value to patients and would improve adherence to recommended therapy. In the United Kingdom, a few virtual clinics have started trials. At London’s King’s College Hospital, 27,000 of their patients have type 1 diabetes but because of the size of this population, individuals cannot receive the medical attention they need. Through Skype or another virtual medium, the virtual clinic allots 20 minutes to each patient and provides them with a specialist nurse or educator to discuss aspects of diabetes management, such as blood glucose levels and insulin administration [11]. The design of the virtual clinic at the Sheba Medical Center is conducted in collaboration with patient advisors. The ultimate goal is to achieve an automated remote follow-up that provides notifications to the medical staff whenever the patient’s clinical values are out of the recommended range. Process evaluation and outcome evaluations are being assessed.

PATIENT INVOLVEMENT: ADVANTAGES AND CHALLENGES

To end the conference, Prof. Karasik led a discussion regarding the advantages and challenges in implementing patient involvement within the healthcare system. The main point to consider, as this trend grows and expands, is that to truly improve objective and subjective outcomes, involvement of patients should be in partnership with healthcare providers.

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Capsule

Interferon for bacterial infections

An early step in the host response to viral infection involves a burst of synthesis of type I interferons that allow cells to quickly fight back against the offending viruses. **Shaabani** and co-authors investigated how the same interferon-stimulated genes (ISGs) that usually help against viruses surprisingly dampen the host’s ability to resist many bacterial infections. Deletion of a single ISG called *Usp18* in mouse dendritic cells

was sufficient in enhancing host control of infections with two strains of gram-positive bacteria. Normal induction of *Usp18* after infection impaired antibacterial responses mediated by tumor necrosis factor. *Usp18* thus represents a potential therapeutic target for control of serious bacterial infections.

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 Eitan Israeli

“We are what we pretend to be, so we must be careful what we pretend to be”

Kurt Vonnegut, (1922–2007), American novelist