

Structural violence and simplified paternalistic ideas of patient empowerment decreases health care access, quality & outcome for ethnic minority patients

Increasing complexity of health care organization, rapid hyperspecialization of medical care, lack of 'patient literacy' and pressure on patients to take over responsibility, challenges political dreams of equal access to patient centered high quality secure care.

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Issue

Patient centered care, health literacy assessments and patient empowerment are interlinked and have gained political momentum in attempts to increase patient satisfaction and quality of care. Clinical experience from The hospital-based Migrant Health Clinic at Odense University Hospital has previously demonstrated how failures in clinical assessment and communication with ethnic minority patients have long term consequences. Inequity in hospital care to ethnic minorities continues to be a challenge with many hidden barriers.

Lessons learnt

- **Hyperspecialized hospital care and time constraints shifts responsibility for coherent patient care to patients and their relatives which introduces a selective hidden inequity for ethnic minority patients**
- **Low patient literacy among health professionals leads to hidden inequities in information, follow-up and possibility for patient empowerment**
- **Hyperspecialization of hospital care, mechanistic ideas of patient centered care & faint ideas of patient literacy threaten to increase inequity in access and outcome for ethnic minority patients**
- **Individuals belonging to ethnic minorities become less literate, lose language skills and quickly develop decision fatigue in case of illness while their networks become less usefull, challenging modern principles for patient centered care**
- **Imperfect models of patient empowerment, incapacitation and intrinsic structural violence in health care threaten equity in health and patient safety**
- **Models of individualized doctor-patient clinical co-production, methods for decision support should be developed**
- **Health professionals should improve their patient literacy (patient knowledge)**

Results/changes

Assumptions behind patient centered care turn out to be insufficient with regard to individual patient needs. Contrary to the intention patient centered care increases patient vulnerability and generates hidden inequalities. Health care systems exercise concealed structural violence in attempts to protect simple routines, limit system challenges, simplify administration and to avoid development of specialized clinical care adjusted for patient subgroups with special needs.

Stressed patients struggle to be granted time for questions, expression of anxiety and to express ambiguities but instead they are met with new information and home tasks. With increasing information load and pressure to take responsibility for decisions regarding treatment patients react with a decision fatigue that frustrates health workers. Low 'patient literacy' of doctors together with a generally low ambiguity tolerance among doctors, jeopardizes communication, confuses patients and lead to misinterpretation of health information - hence patient questions are regarded as irrelevant and discarded as "cultural misperceptions".

Normally patients' relatives are regarded as necessary partners of patient care but for ethnic minority patients relatives are regarded as irrelevant 'interpreters' and hence discarded. Patients often lack a functional social network of relatives willing and able to assist.

Hyperspecialization, strict adherence to referral criteria and protection of department routines exclude ethnic minority patients with multiple diagnoses, unexplained symptoms and a weak social network from normal quality specialized care. Time constraints shifts responsibility for coherent patient care to patients and their relatives which introduces a selective hidden inequity for ethnic minority patients.

Varying organization, speed and expectations of patient involvement between departments confuses ethnic minority patients leading to their incapacitation, medical errors and no-shows. Medical errors and patient errors are regarded as "expectable" and "unpreventable" by health workers because of unchangeable language and cultural barriers, hence not reported. Likewise, lack of interpreter use is regarded as an error as it is seen as a patient problem not a hospital problem.

Invitations to patient engagement in decisions can be anxiety provoking but are also regarded as "No-no" options, hence patients feel deceived into already selected choices and consequences that are too complex and overwhelming.

Ethnic minority patients are excluded from patient user satisfaction surveys because they are unable to read or refuse to participate because of fear of retaliation from social services or withdrawal of residence permits.

Description of the problem

In a continuous effort to identify in-hospital barriers to equal care we conducted qualitative analysis of selected patients with complex somatic conditions investigated in multiple hospital departments. The patient cases analysis was conducted in real-time and indicates synergistic barriers to equity in hospital care for ethnic minority patients

