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The informed patient/ citizen: a new partner in the political health arena

Parallel Forum V the informed patient.doc / Thomas Kaltenbacher

Medienbetreuung:
Dr. Carmen Kiefer - Medienservice
Pressebüro Bad Gastein
Tel.: +43 6434 30250
Fax: +43 6434 30253
+43 6434 253566
Mobil: +43 676 344 9971
113162.437@compuserve.com
www.ehfg.org

Be informed!

How informed patients and citizens should be included in health policy

“Improving health information and knowledge” is a declared aim of the European Commission’s health policy. In the age of telecommunication societies have turned into information societies worldwide. Information is the motor of every functioning social system and should enable people to equally profit from new resources made available to the public for the first time in history. Yet, the weakest members of society, ill and sick citizens, are left out of this global indulgence. Health policies of past governments have failed to acknowledge the importance of informing patients and present governments are now eager to catch up on this issue.

Defining the information needs of patients and citizens

Health services around Europe should be patient- centred, inform and involve patients according to Professor Angela Coulter from Oxford’s Picker Institute, who has presented a survey on information needs of patients and citizens in the UK. In her opinion, information flow to and from patients is essential to make improvements in the health system. Patients, who are left alone with their anxieties and concerns, feel betrayed by the National Health System. Without the important feedback from patients, however, the NHS is not able to tackle the right targets. If the ‘communication loop’ between policy makers, providers and patients, respectively all citizens, is not improved future decisions will continue to fail the aim of closing the information gap.

Findings of a quantitative and qualitative research study in Spain carried out by the Josep Laporte Foundation and the Universita Autonoma of Barcelona overlapped widely with those of the British survey. Albert J. Jovell confirmed that the most important source of information for the patients is the patient-physician relationship.

Access Denied in the Information Age

The internet was also mentioned to be a source for useful information despite its prevailing disadvantages such as accessibility and poor quality of information as well as bias of websites through the medical industry. Individually distinguished, good quality information still seems to be difficult to obtain for the patients, the best source of information being still the doctor. Yet doctors have little time due to the high demand of productivity. This 'conveyor belt surgery' makes evidence based medicine and the obligation to inform practically impossible.

The Right to Health

In 1994 the WHO made the "Declaration on the Promotion of Patients' Rights in Europe" in the Amsterdam Consultation. Yet, where is the evidence? This was asked by Anne Brunner and Manfred Wildner in a survey of the Bavarian Public Health Research Centre in collaboration with the Universities Eichstätt and Munich. The main aim of the presentation was to show regional and gender-specific differences in the fulfilment of patients' rights. The results from interviews with patients in Germany, Switzerland and Austria on how they had been treated in respect to information, confidentiality, privacy and values in health care showed deficits especially as far as information rights, hospital transition and humane terminal care were concerned. Regional differences proved to be more pronounced than single gender-specific differences. Switzerland showed the best results followed by Austria and Germany.

Tribunal for Patient's rights in Italy

Ms Teresa Petrangolini from the Tribunale per i diritti del malato gave an appealing presentation of how citizens can be involved in the decision-making process in health policies. Starting out with how new citizenship has improved its influence by gaining powers and responsibilities and by taking health matters into their own hands Ms Petrangolini showed how citizens can become active in public policies. Activities of such citizenship have reached some of their objectives by means of organising themselves and exercise power for the protection of rights. The Tribunal for Patients' Rights is a social movement, which emerged in the 1980s and has grown to 10.000 members working in hospitals and territorial services across Italy. Use of a networking system has enabled the Tribunal to coordinate its actions and to recruit new members. It is their aim to enforce improvements in the health sector for which they have adopted issues raised in European documents such as the Maastricht and Amsterdam treaties or the Ljubljana Charta on Health Care. Through cooperation with other social movements in Italy such as the Cittadinazattiva, founded in 1978 and counting 180.000 members, citizens in Italy have a strong tool to guarantee their role in public affairs according to Ms Petrangolini.

The European Experience

Dealing with the European Commission in matters of health policies can be a difficult task as Mr. Rodney Elgie, former commercial lawyer and president of GAIMAN (Global Alliance of Mental Illness Advocacy Networks) has shown in his speech. He outlined governments' tendency to deal with health matters only on short terms, i.e. one election period of up to four years. Chronic conditions of 10- 15 years are hardly dealt with. In the field of mental diseases such as depressions, etc. politics have thus failed to provide an applicable health policy. Patients' needs are not understood and patients are not even asked to involve in a field where they themselves are the experts. Some diseases are not even acknowledged as such and the estimated number of "hidden patients" suffering from "hidden diseases" reaches 59,1 millions in Europe. Hence patients often remain without care and do not come forward with their disease, which leads to attempts of self-cure with alcohol or drugs- and often to suicide (90% of suicides committed in Europe are likely to be linked with mental illnesses). These factors conjure up "hidden costs" resulting from unemployment, crimes and the like.

Until now the European Commission also failed to tackle this issue in their working groups, none of which seems to be responsible. Only recently, when mental disease workgroups joined in with neurologists, psychiatrists, neuro surgeons, industry representatives and the AOK, Germany's largest public insurance company, a research programme was introduced by the EC. "It is hard to get through in the EC" commented the EC's former commissioner of social affairs, Pàdraig Flynn.

And in the U.S.?

Another desolate health system is the American one, stated David Lansky PhD. The US public is seen rather as a tactical element in a battle for power and money among industry stakeholders than as a source of expertise or moral influence on the health system. Lacking a central health policy mechanism most health matters are delivered to the private sector, resulting in poor quality of treatment- the 7th leading death cause in the US is medical error.

Health organisation have thus set up their goal to involve all US citizens in care as "activated customers" to improve conditions. The way to encourage citizens (as future patients) is to inform through various media (e.g. the internet), to gather experiences from carers and to set up guidelines for a standardized medical treatment. Citizens are also encouraged to involve by raising fear through suggestions like "medicines are wrong, tests are wrong, diagnoses are wrong" and the conclusion is: "Be alert. Ask questions. What you don't know can kill you!"

Strategies of the European Commission (EC)

'The 16th of May 2000 has brought a new emphasis on concerns about health policies' promised Walter Baer, assistant to the director of Public Health. Consequently, proposals for a new programme on Public Health can be

contributed to a EC consultation document due in February 2002. In a European Health Forum (not the one in Gastein, the name is just an unfortunate coincidence) these proposals will be evaluated. This Forum will have three subgroups: a policy forum, a virtual forum and an open forum (again an unfortunate name) for who is going to be in this open forum will be decided by the EC.

Hence who will sit in this forum and under which criteria will be selected is still a controversial matter.

Things to do

In a concluding summary the chairman of these session, Prof. Stipo Oreskovic of the Zagreb University, has brought the issues to a key message: The participation of citizens and patients in patient- oriented health policies is essential to tackle the serious crises of health care in the entire world. Expertises from the US and European countries should be evaluated to create a health system of which the key and not the option should be the patients and citizens of all countries.