

**DOES PROVISION OF AN EVIDENCE-BASED
INFORMATION CHANGE PUBLIC
WILLINGNESS TO ACCEPT A SCREENING
TEST?**

Gianfranco DOMENIGHETTI

January 1999

Cahier no 9901

ABSTRACT

The basic requirement for patient decision making is the provision by the physician of an essential relevant and understandable information (Evidence Based) allowing him to decide whether he wish or not to receive the proposed treatment.

This analysis shows that the willingness to undergo a doubtful screening test (about 70 % false positive responses) for a rare cancer by the general population change dramatically (60% versus 13,5%) according to the quality of information provided. This result, facing the impressive increase of diagnostic and screening procedures, could have important economical, ethical, clinical, public health and legal implications.

Acknowledgements

This research was supported by a grant from the Helmut Horten Stiftung, Villalta, Madonna del Piano, Switzerland. I'm particularly grateful to Dr. Roberto Grilli, Mario Negri Institute, Milano and Dr. Jenny Maggi, Institute of Social Psychology, University of Geneva for their help in data analysis and to Prof. Alberto Holly for useful comments on the manuscript.

Keywords Health Care Markets; Information; Decision Making; Doctor-Patient Relationship; Screening; Diagnostic Procedures; Evidence Based Medicine; Public Health.

JEL classification: I 100, I 111

Does provision of an evidence-based information change public willingness to accept a screening test?

Gianfranco DOMENIGHETTI

Universités de Lausanne et Genève et

Sezione Sanitaria, Dipartimento delle Opere Sociali, 6500 Bellinzona

Introduction

Over the last years there has been an increasing consensus in considering that patient preferences should play an essential role in clinical decision making [1]. Indeed patient autonomy tend to be acknowledged as a value "per se". However the basic requirement is the provision of an adequate information on the yield of the health care intervention proposed. From the consumer side, a want for health translated into service consumption implies a demand for information about effectiveness, adequacy, risks and benefits and possible alternatives. The lack of knowledges about these aspects causes in consumer-patient an amount of anxiety about making a wrong decision which could have adverse health outcomes [2]. Without an adequate level of relevant information the patient tends to accept acritically every procedure proposed not only to maximize health benefits but also (in particular for diagnostic and screenings services) in the aim to "minimize regret". This last could be a rational choice under uncertainty due to a lack of information that could be relevant for decision making [3].

While Wolf already showed that giving patients balanced information can change their intention in undergoing screening tests for prostate cancer [4], we explore whether the same holds true when the target of the information is not the individual in a real patient-doctor encounter, but the general population at large exposed to a generic information, as it is usually the case for messages conveyed through public health interventions.

Methodology

On May 1998 a mailed questionnaire was sent to a representative sample (N=1000) of the Swiss general population aged over 20. Response rate was 87%. Participants were randomly allocated in two groups to receive "basic" (N=401) and "extended" (N=466) information about a screening test for pancreatic cancer and were asked to express their willingness to accept the screening procedure.

This particular type of cancer was chosen because (i) it affects both 2 sexes, (ii) a blood test kit with poor sensibility and specificity is available (tumour marker CA 19.9) (iii) the annual incidence of the disease is relatively low and (iiii) the survival at 5 years is very poor.

The two scenarios (“basic” and “extended”) provided respectively to the two groups of respondents, were:

Basic information scenario: "During a routine consultation the doctor ask you if you are willing to accept a diagnostic test (consisting in a simple blood examination) able to identify early if you have a pancreatic cancer (that means that the disease will be identified before you experience any symptoms)".

Extended information scenario: in addition to the basic information the respondents of this group were provided with the following:

"The doctor inform you also that: (i) the test is not very accurate, only 30% of those testing positive have pancreatic cancer; (ii) as a consequence of that all those testing positive will have to undergo additional examinations (including MRI) in order to confirm the diagnosis of cancer. This will require admission to hospital; (iii) every year in Switzerland about 11 persons every 100'000 have a confirmed diagnosis of pancreatic cancer; (iiii) pancreatic cancer can practically not be cured (out of 100 diagnosed only 3 are still alive at five years).

Respondents could chose among the following options: (1) I am willing to accept to undergo the test; (2) I will not accept; (3) Before making a decision I would ask for a second opinion.

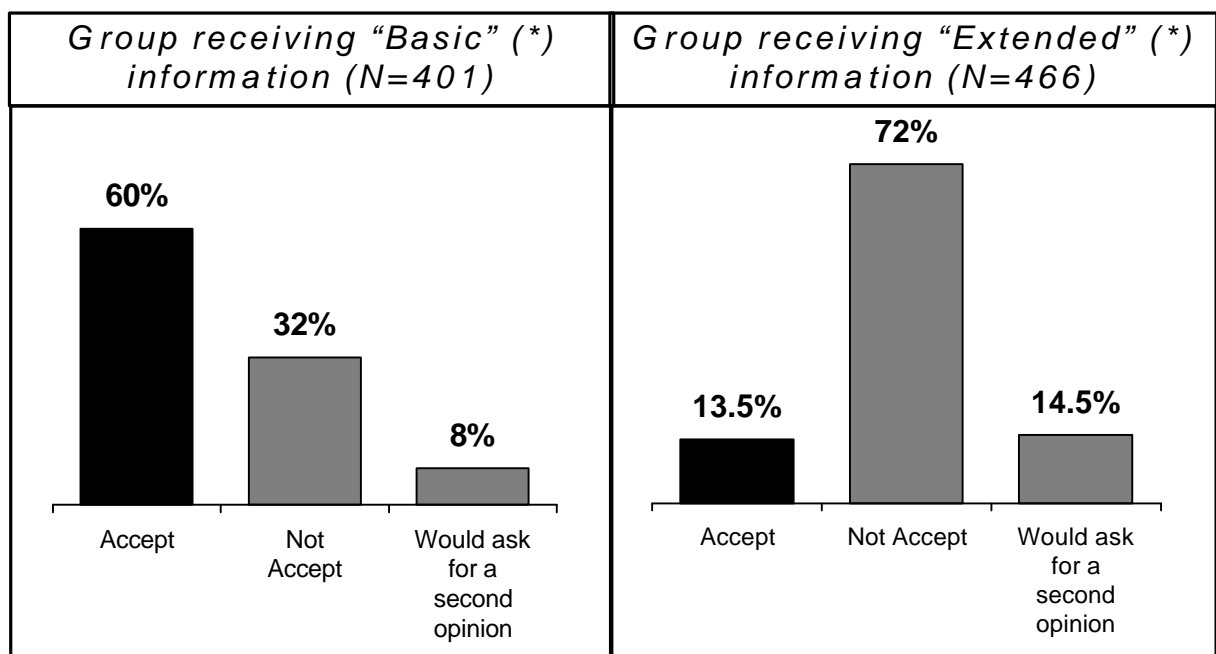
Results

Characteristics of respondents were similar in the two groups (see [Table](#)).

Characteristics	Information Groups		P. Value
	"Basic" N=401 (%)	"Extended" N=466 (%)	
Age (mean, SD)	45.2 (+/- 15.63)	45.02 (+/- 14.44)	0.40
Sex:			
- male	39	41	0.56
- female	61	59	
Education:			

- high - middle - low	12 46 42	11 44 45	0.64
Language: - german - french - italian	72 21 7	68 20 12	0.06
Type of doctor-patient relationship: - active - collaborative - passive (*)	10 73 16	11 70 18	0.71
Having recent experience of cancer among relatives and friends:	16	19	0.23
Perceiving medicine as an "exact" science (**)	52	54	0.82
<p>(*) Respondents who agreed with the following statements: <u>Active role</u>: "After I have listened to my doctor's opinion, I make my own decision about the treatment option I would like to receive". <u>Collaborative role</u>: "My doctor and I, together, decide on the type of treatment I will receive" <u>Passive role</u>: "I leave the decision on the type of treatment to my doctor". (**) Respondents who agreed with the statement: "The medicine is an exact (or almost exact) science". NS=Not Significant</p>			

As expected (Figure) only 13,5% (N=63) of those receiving the "Extended" information stated their willingness to accept the test, as compared to 60% (N=237) of those exposed to the "Basic" one (P<0,001).



Willingness to undergo a screening test for pancreatic cancer.

*see text

After adjusting for respondents characteristics through a logistic regression model allowing the

expression of the “information effect” in terms of odds ratio (OR), provision of additional information was related to a 91 % (95%CI; -87% to -94%) relative reduction of the likelihood of accepting the diagnostic test. Some personal characteristics appeared to be related to the acceptance of the test, regardless the amount of information provided. In particular, males were more likely to report their willingness to accept (OR 2,19; 95%CI: 1, 52-3, 16) as well as those with a passive (OR 3,57; 95%CI: 1, 74-7, 31) or collaborative doctor-patient relationship (OR 2,00; 95%CI: 1,09-3,68). Those of German language were also less willing to accept (OR 0,54; 95%CI: 0,36-0,80). Respondent's level education was not found related to willingness to be tested.

Comment

These results clearly show that the willingness to accept to undergo a test of questionable value is predicted by whether or not the public has been exposed to an “extended” level of information, although not personalised as it is usually the case during a medical consultation. We could say that information has a “protective” effect. According to these findings, about 80 % of individuals who would have agreed to undergo the test when exposed to “basic” information would change their mind after knowing more about the clinical implications of the test.

This last shows that content of information released is essential to over or under-estimate the real risk, as Viscusi has pointed out for smoking and lung cancer [5].

Nevertheless the 60% (among those receiving “basic” information) agreeing to undergo a screening procedure for a rare cancer with very poor outcome is of concern. It shows how many consumers are bound to act acritically in front of every diagnostic procedure proposed, possibly due to their overoptimistic and “mythical” expectations.

This calls for the central responsibility both of institutions and doctors in providing the public and individuals with relevant evidence-based information. This could have two desirable effects, (i) make consumers/patients more aware about the real clinical effectiveness of the interventions proposed, and thus less exposed to the risk of accepting procedures of questionable value; (ii) to allow informed choices to find options more likely to fit with patient’s values and preferences.

Facing the impressive increase of diagnostic procedures [6], screening practices [7], and the implementation of predictive medicine in the near future, it seems to be essential to develop a global strategy to enable a more active consumer role in clinical decision making, even among those who, because of their cultural attitudes, are more prone to rely completely on the subjective opinion of their own doctor. Provision of comprehensive research-based information can maximise patient freedom and autonomy in decision, allows a true “informed” consent, and can minimise the use of inappropriate or questionable diagnostic procedures and avoid waste of resources.

From a public health perspective these results highlight the need for community interventions aimed at empowering and encouraging the public to ask physicians the “right” questions before undergoing any suggested procedure [8]. Such a programme is currently ongoing in the Swiss region of Ticino, where, through a booklet targeted to all households [9], the consumer-patient is

prompted to ask physician the following questions before undertaking any diagnostic test:

1. Which disease (or illness) can you detect through the diagnostic test proposed?
2. What are the probabilities you will not get a false-positive or false-negative result?
3. Is the disease (or illness) you can detect curable? And what are the probabilities of success?

There is already some empirical evidence that this approach can be successful. In 1984 a public information campaign in Canton Ticino (Switzerland) decreased hysterectomy rates by 26% [10] and a systematic review confirmed the effect of mass media campaigns on health service utilisation [11].

In practical terms it could be feasible to develop, at least for the more frequently performed screening tests, a minimum set of evidence-based information the physician should deliver to each patient, allowing the time to reflect on before giving the informed consent.

Finally, these findings imply that the content of the currently produced leaflets and supports aimed at promoting community screenings should be carefully reviewed and critically assessed, to minimize the potential risk of misleading the consumer-patient [12].

References

- [1] Entwistle VA, Sheldon TA, Sowden A, Watt IS. Evidence-informed patient choice. Practical issues of involving patients in decisions about health care technologies. *Inter J Technol Assess Health Care*, 1998; 14: 212-225.
- [2] McGuire A, Henderson J, Mooney G. The economics of health care. Chapter 3: Health care as an economic commodity. London, New York: Routledge and Kegan Paul, 1988: 33-34.
- [3] Belle David E. Regret in decision making under uncertainty. *Oper Res*. 1982; 30: 961-81.
- [4] Wolf AM. Impact of informed consent on patient interest in prostate-specific antigen screening. *Arch Intern Med* 1996; 156: 1333-6
- [5] Viscusi WK. Smoking: making the risky decision. Oxford University Press, Oxford, 1992.
- [6] Black WC, Welch HG. Advances in diagnostic imaging and overestimation of diseases prevalence and the benefits of therapy. *N Engl J Med* 1993; 17:1237-43
- [7] U.S. Preventive Services Task Force. Guide to clinical preventive services. Alexandria, Virginia: International Medical Publishing, 1996
- [8] Domenighetti G, Grilli R, Liberati A. Promoting consumers' demand for evidence-based medicine. *Int J Technol Assess Health Care* 1998; 14: 97-105
- [9] Dipartimento delle opere sociali. I SI e i NO della Salute. Cantone Ticino, Bellinzona 1998
- [10] Domenighetti G, Luraschi P, Casabianca A, et al. Effect of information campaign by the mass media on hysterectomy rates. *Lancet* 1988; ii: 1470-3
- [11] Grilli R, Freemantle N, Minozzi S, Domenighetti G, and Finer D. Impact of mass media on health services utilisation. *Cochrane Library Issue 3*. 1998. Oxford, Update Software.
- [12] Foster P, Anderson CM. Reaching targets in the national cervical screening programme: are current practices unethical? *Journal of Medical Ethics* 1998; 24: 151-7