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### Informing the patient: the “forgotten” link



In the last decades, researchers and clinicians shared great level of information regarding scientific evidence. For example, efforts to improve the communication between researchers and clinicians have been made by the Enhancing the Quality and Transparency of health Research Network, with the publication of several guidelines to improve the quality of reporting of research [1]. Furthermore, the Cochrane Collaboration has been actively publishing over the years high-quality systematic reviews for researchers and clinicians [2]. Similarly, clinical guidelines have been developed with robust methodologies [3] to support clinicians to make more evidence-based decisions in the treatment of their patients. But, what documents are available to the patients? A patient seeking for some clinical treatment may raise important questions such as “how can I find clinical guidelines that “speak my language” to help me on the decision of my treatment?” or “how can I better understand published research findings?”

The idea of a shared decision making, that is, the clinical decision made by both clinician and patient, is only adequate when both parties have comprehensive knowledge about potential benefits and harm of therapies. It is unquestionable that clinicians detain more comprehensive and in-depth information than patients, but one can argue whether this is a fair relationship. The side detaining more information will likely tend to bias the discussion on therapies, eventually leading to a biased clinical decision toward its preference.

So far very few efforts have been made to reduce the gap of knowledge between specialists (i.e., researchers and clinicians) and the lay audience (patients). One example is the partnership made by the Cochrane Collaboration and the Wikipedia [4] where the Cochrane Collaboration claims “to improve the reliability and accessibility of Wikipedia medical information online.” Nevertheless, in its current stage, the project seems not to be fully available. It is therefore clear that new approaches to better inform patients are urgently needed.

One approach to reduce this gap of knowledge would be the development of guidelines for reporting research such

as Consolidated Standards of Reporting Trials, but tailored to the lay person who has no or only superficial knowledge on methodology of research. The main structure of existing guidelines could be used by editing them in a language that a lay person can understand. Thus, an explanatory document describing in detail the items could be also provided (like in the original document for researchers) [5]. Similarly, existing high-quality clinical guidelines (such those developed with Grading of Recommendations Assessment, Development and Evaluation) and other relevant scientific tools could be “replicated” in a language where the lay patient can adequately understand the information.

A potential barrier for this approach is the potential conflict of interest of clinicians. Patients better informed will probably question more the effectiveness of treatments, and many procedures which are currently performed will not be accepted by patients. For example, in circumstances when clinicians provide self-pay services to their patients without sound evidence supporting these services (mainly in the case of tests for screening cancer and other diseases) [6].

The reduction of the gap of knowledge between clinician and patient will generate a more ethical and informed shared decision-making process.

Clovis Mariano Faggion, Jr.

*Department of Periodontology and Operative Dentistry*

*Faculty of Dentistry*

*University of Münster*

*Waldeyerstraße 30, 48149 Münster, Germany*

Tel.: +49-(0)251-83-47061; fax: +49-(0)251-83-47134.

*E-mail address: clovisfaggion@yahoo.com*

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