202

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A-B-PEE: HOW MANY CAN READ OF THOSE WE WANT TO TREAT?

Hypothesis / aims of study

In the current digital world where innovations quickly follow each other and increasingly people have to rely on texts and self searches for information, there is a group of patients that cannot keep up. Low literacy skills and Health Illiteracy (HI) that comes along with it, result in several health issues. HI patients tend to have less knowledge on health in general as well as on alarm symptoms. They are less able to come to an optimal treatment choice, as their ability to profit from (digital) decision support tools is low. Furthermore, costs rise by a higher number of cancelled operations and no shows on one hand, but in total more hospital visits on the other [1]. In the European Union these costs are estimated to be 350 billion Euros each year, while globally it is estimated to be over 1.1 trillion euros [2].

In functional urology, we depend heavily on information provided by patients themselves through voiding diaries and self-administered questionnaires. Treatment choices have to be made after patients are well informed as most medications have adverse effects as well, improvements might only be limited, and expectations of operation results may differ from reality. In all this, HI is a problem that hardly gets any attention, while research for example showed an understanding of the medical term 'incontinence' to be only 5% (and 'erection' 50%) in HI patients [3]. As HI patients not easily come forward, doctors do not recognize them and more and more information goes by leaflets and website texts, the impact of HI on health and treatment outcome is not likely to improve any time soon.

With this in mind, we investigated the incidence of health illiteracy using three different sampling methods.

Study design, materials and methods

In a period of one week, all patients over the age of 16 visiting our outpatient clinic (N=327, 82.2% male) were asked to fill out the validated and anonymized Set of Brief Screening Questions (SBSQ) while waiting for their appointment. The SBSQ consists of 3 questions regarding help needed while reading medical information, while filling out medical forms and while trying to find medical information themselves. Scoring is via a 0-4 Likert scale and HI is defined as a mean score of 2 or less. Additional information, e.g. regarding native tongue was collected. Patients visiting our clinic were supposed to well mimic average Dutch population as they originate from a large city as well as from rural areas surrounding it.

To exclude the possible bias of non-response by health illiterate patients not being able to complete the questionnaire, all non-responders were randomized and 11% were contacted by phone to fill out the SBSQ by telephone interview (N=37, 83.8% male, median age 65.4 years (IQR 60.5-70.4)).

To test a possible bias of sampling method, two doctors interviewed all their patients in the medical office during their consult and filled out the SBSQ (N=163, 65.4% male, median age 65.0 years (IQR 49.0-75.0).

We analysed the incidence of health illiteracy and compared the sampling methods patient-filled-out versus doctor-filled-out (telephone interviews and medical office) by using Pearson Chi-Square test in SPSS 20.

Results

140 Questionnaires were returned (response rate 43%, median age 62.6 years (IQR 23), 81.8% male), proving 8.6% to be HI.
The non-responder analysis (response rate 100%, median age 67.0 (IQR 23), 83.8% male) showed a 10.8% HI.
HI incidence proved not to differ between both groups (p=0.133).
163 Questionnaires filled out by the doctor (response rate 100%, median age 64.0 (IQR 26), 68% male) showed 13.5% HI.
HI incidence proved not to differ between questionnaires filled out by patient or by doctor (p=0.160).
Overall HI incidence was 11.5%.

Interpretation of results

For the first time, incidence of health illiteracy in the urologic population is studied. 11.5 Percent of the studied population proved to be health illiterate, resulting in problems with informed, shared decision making and additional high costs. Three different sampling methods didn't show significant differences in incidence; thereby in our opinion the outcome is reliable.

Concluding message

In a representative Dutch urological clinic, HI proved to be well over 10%. With high education rates in the Netherlands, HI numbers are expected to be even higher in other parts of the world. This may have huge consequences on functional urology practice. Awareness of the problem as well as special attention for HI patients by adapting information materials and intensifying efforts to reach informed consent is of the utmost importance. Surely, lowering HI will benefit functional urological outcome measures, decrease costs and eventually lead to a higher proportion of satisfied patients.

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