Statistical literacy: Reasoning patterns in the concrete case of genetic testing

Name: Jelle J.M. Nuijten

Student number: 3164071

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Supervisor: Dr. Elwin R. Savelsbergh

Course coordinator: Dr. Dirk Jan Boerwinkel

Second examiner: Dr. Dirk Jan Boerwinkel

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Jelle J.M. Nuijten

Master student Science Education and Communication, Utrecht University, Utrecht, the Netherlands

Freudenthal Institute for Science and Mathematics Education, Faculty of Science, Utrecht University, Utrecht, the Netherlands

Abstract

Various situations in everyday life require risk-assessments, in which probability, uncertainty and chance phenomena play important roles. Although aspects of statistics and risk are being addressed in various school subjects, the current practice in secondary education falls short of developing students into statistically literate citizens. It is unclear what such literacy would imply in concrete real-life situations. The aim of this research was to gain insight in the reasoning patterns of various types of statistically literate citizens to provide a more practical basis from which learning goals for education could be specified. To reach this goal three biology teachers, three math teachers and three clinical geneticists were subjected to a think aloud protocol while dealing with a Socio-scientific issue selected from a newspaper article. Afterwards they were interviewed regarding their vision and professional practice. Vignettes from the experts' reasoning patterns were created. Results show different reasoning patterns leading to similar conclusions about the newspaper article. Furthermore, context knowledge positively influenced the amount of critical questions asked, as well as respondents' confidence in posing these questions. Implications for education predominantly point to improving transfer of students' knowledge between Math and subject classes and attention towards different beliefs and attitudes.

Key-words: *Statistical literacy; Socio-scientific issue; genetic testing; Think aloud protocol; Vignettes*;

Introduction

In our daily lives, there are a great number of situations where probability, uncertainty and chance phenomena play major roles (Gal, 2005). To reach an opinion or decision in such situations an informal reasoning pattern is followed (Sadler & Zeidler, 2005). Informal reasoning is characterized by reasoning about consequences of actions and trying to find a stance or decision by weighing the different pros and cons. The first, emotional, response (preference or decision) in these situations will be an intuitive one based on a personal perception of the risks involved (Slovic, 1999). This perception of risk will be based on a person's beliefs and attitude towards the issue and on pre-existing knowledge. However, perceptions of risk are vulnerable to bias (Pratt et al., 2011) and also objective arguments and other people's opinions need to be weighed into this preference or decision. For this reason, discussing and/or reflecting on these issues is also required (Steen, 1999, 2001; Wallman 1993). The ability to interpret and critically evaluate outside information involving probabilities, compare this information to one's personal opinion and draw conclusions about the implications of this information is often referred to as a person's statistical literacy (Gal, 2002; Wallman, 1993; Watson, 2003).

One major purpose of secondary education is to provide students with the literacies they need as a citizen. It is widely felt that, although aspects of statistics and risk are being addressed in various school subjects, the current practice in secondary education falls short of developing students into statistically literate citizens (Watson, 2003). In fact, although we have a general, theoretical, definition of statistical literacy, it is not very clear what it would take to act as a statistically literate citizen in a real-life situation. Most studies looking into specific cases from this perspective have been showing learning goals and students' abilities to reach those goals, instead of looking into societies' demands from them (e.g. Sadler & Zeidler, 2005; Zeidler & Keefer, 2003). Other studies focus more on errors and misconceptions, like the representatives misconception or gambler's fallacy (Tversky & Kahneman, 1974), preventing the proper use of statistics (for a comprehensive overview, see Garfield, 2002). First steps in a more practical approach have been taken by the TURS project. Deborah's Dilemma, for example, has been developed to model thinking about risks. It is mainly used to reflect on how decision making processes work and what the reasoning behind certain outcomes is (e.g. Kent, Pratt, Levinson, Yogui, & Kapadia, 2010). However, this does not yet cover what makes someone statistically literate and which reasoning patterns students should learn to use (and subsequently how to best achieve those).

Therefore, a concrete operational definition of the learning goals for statistical literacy would be a first requirement to improve education.

A person's statistical literacy influences how adequately one can respond to situations in which risk-assessments play a major role. There are risk-assessment situations in which all variables are clearly present and have just one interpretation. However, most important decisions citizens have to make require a more difficult risk assessment where this is not the case. Examples of these decisions are so-called socioscientific issues (SSIs), which are "open-ended, ill structured, debatable problems subject to multiple perspectives and solutions" (Sadler & Zeidler, 2005, p. 2). SSIs are characterized by a debate of benefits versus risks in a certain issue and are influenced by emotions and beliefs when weighing these (dis)advantages. SSIs can pose dilemmas in which the risks and benefits are personal (e.g. do I undergo a certain type of surgery?), invoke social debates in which the risks and benefits are influencing the entire society (e.g., do we implement laws to control global warming?) or involve a combination of both (e.g., a parent taking a stance about a vaccination program). To further complicate the issues, information about these issues is presented in different kinds of qualitative and quantitative data with different levels of certainty by sources of differing perspectives and quality (Pratt et al., 2011). The abilities a person should have to come to an argumented decision or stance in SSIs correspond precisely to those of statistical literacy and are therefore a perfect tool to use in the present day classroom. This, amongst other reasons, is why SSIs have become important in science education and the promotion of scientific literacy (Sadler & Zeidler, 2005; Zeidler & Keefer, 2003).

The operational definition of statistical literacy defines the knowledge, skills and attitudes, that are required to handle a real-life statistical problem. For this research the real-life statistical problem involved an SSI in the form of a newspaper article that gained wide public attention. The purpose of the current research is to provide an operational definition of statistical literacy for this concrete situation to enable a comparison between what is expected to be taught to students, with the actual implementation of statistical literacy in the shared curricula of subject- and math teachers.

Theoretical Framework

An operational definition of statistical literacy will describe which knowledge, skills and attitudes citizens should possess to be considered statistically literate. This operational definition will describe a broad array of competencies, which will be categorized to create a comprehensible overview and show the relations between the different competencies. This allows, for example, curriculum goals to be derived from them and teaching methods to be constructed. To create a starting point for this concrete operational definition, an abstract framework for statistical literacy can be used to guide analysis and classification of the data. The most suited framework for statistical literacy needs to capture both the education and the practice of statistical literacy, to be able to give insight into the implementation of its education in this and in further research.

Multiple frameworks from different points of view have been developed to describe statistical literacy in an abstract manner. The frameworks by Gal (1994, 2002, 2005), Watson (1997, 2000, 2003) and Makar and Rubin (2009) have been developed with education as their focal point. Makar and Rubin (2009) consider primarily informal inferential reasoning in statistics. This is defined as the process of making probabilistic generalizations from data that extend beyond the collected data. This framework does not include different emotions and attitudes that are less important for the skill of inferential reasoning, but are indispensable when talking about citizenship.

The frameworks of both Gal (1994, 2002, 2005) and Watson (1997, 2000, 2003) use a description of statistical literacy that can be divided into knowledge, skills and attitudes required to work with the different types of information we come across in our daily lives. However, because of different starting points of view, the frameworks have been built up quite differently. Watson (1997, 2000, 2003) has described statistical literacy from a developmental psychology perspective. This is why Watson’s framework puts more emphasis on a hierarchy of knowledge and skills associated with statistical literacy which develops over the years. Gal (2002, 2005), on the other hand, has described a framework of building blocks of statistical literacy “on the basis of literature review on writings by mathematics and statistics educators, as well as other sources on scientific literacy and sources discussing mathematics and statistics in the news” (Gal, 2002, p.10). Gal’s framework focuses more on the joint activation of the elements in his framework - which have to work in interaction with each other - to enable people to interpret and critically evaluate outside information and consider the implications of this information. For this study Gal’s framework is most relevant and useful as a starting point.

The framework proposed by Gal (2005) is divided into knowledge elements and dispositional elements. The knowledge elements are not isolated units of knowledge but work in interaction with each other. Gal (2005) distinguishes “big ideas”, “figuring probabilities”, “language”, “context” and “critical questions” as knowledge elements and will be used in this framework according to the following definitions.

- **Big ideas**. Important, often abstract, concepts which are essential when communicating about statistics (e.g. randomness, variation and independence).
- **Figuring probabilities.** The skills needed to integrate information from multiple sources (including non-probabilistic information) in order to reach an understanding of probabilistic statements and to generate estimates about the likelihood of events. Important additions to this concept are the notion of evidence and its quality and the level of confidence and uncertainty.
- **Language.** An understanding of different terms (e.g. the difference between "low risk" and "lower risk than") and methods (e.g. diagrams and graphs) used to communicate about risks.
- **Context.** The ability to interpret and link probabilistic information to different situations. There is a need for familiarity with the non-statistical concepts involved, in order to understand the impact or implications of probabilities (e.g. a 80% chance to survive surgery could be high or low dependent on the type of operation).
- **Critical questions**. These are questions that need to be asked when encountering probabilities: There needs to be an awareness of the writer's purpose, objectivity and reasoning. Also the methodology should be questioned, as the quality of a study's results depends on it (this involves typical problems and biases).

The dispositional elements are defined as "the inclination to activate the five knowledge bases or share with others his or her opinions, judgments, or alternative interpretations" (Gal, 2002, p.17). They are required to use the knowledge elements. The dispositional elements Gal (2005) describes, namely a "critical stance", "beliefs and attitudes" and "personal sentiments regarding uncertainty and risk", determine a person's motivation to use the knowledge elements.

- **Beliefs and attitudes.** Underlying factors determining the willingness to invoke action. This willingness to invoke action applies to different parts of statistical literacy.
    1. For a person to invoke one's statistical knowledge, one has to believe statistics can be a useful tool in helping with socioscientific issues. That not only emotions should play a role, but that statistical facts should also have an impact.

2. Someone will also have ideas and opinions about statistics (e.g. government statistics are always accurate) that will influence, for example, a critical stance in different situations.

- **Critical stance.** Here Gal's (2002) interpretation of Frankenstein (1989) will be followed. It states that a critical stance describes "a first expectation that adults hold a propensity to adopt, without external cues, a questioning attitude towards quantitative messages that may be misleading, one-sided, biased, or incomplete in some way, whether intentionally or unintentionally" (Gal, 2002, p. 18).
- **Personal sentiments regarding uncertainty and risk.** Gal's (2002) interpretation of this element is aimed at the willingness to learn statistics: "Action or reaction in such situations may involve taking some personal risks, i.e., exposing to others that one is naive about, or unfamiliar with, certain statistical issues, and possibly suffering some embarrassment or the need to argue with others."

The elements described above serve as a framework to categorize the knowledge, skills and attitudes that will be shown by the different respondents. The framework is used to differentiate between statements of different categories (i.e. attitude or skill) or between different statements within the same categorie (i.e. two statements involving skill), allowing for accurate description of relations between statements in a comprehensible overview.

Following the definition of statistical literacy, statements regarding one's personal opinion are to be expected. Furthermore, citizens are expected to weigh in emotions, when handling an SSI. It could be argued that beliefs and attitudes cover these emotions. Beliefs and attitudes, however, are more long-term while emotions are short-term and are subjected to more changes in time. Gal's (2005) interpretation of "Personal sentiments regarding uncertainty and risk" is an attitude to "learn to use statistics". However, following the reasoning above, it is more practical to place this attitude of "learn to use statistics" as a third category under the "beliefs and attitudes" category (see figure 1).

Personal sentiments regarding risk and uncertainty in this research will be defined as having risk seeking or risk averse behavior; what a person's action will be, given a certain likelihood of an event. Numerous factors, including beliefs, attitudes and emotions influence someone to express this risk averse or risk seeking behavior. To further clarify personal sentiments regarding uncertainty and risk in this research, the following example regarding the implications of the information might be helpful.

Where 20% death rate on a certain operation will be acceptable for some (e.g. a young person with a lot of pain and no other chance of recovery), it can also be perceived as too high by others not facing the same situation. This means that how this 20% is valued greatly varies between individuals and therefore influences the meaning of statistical information.

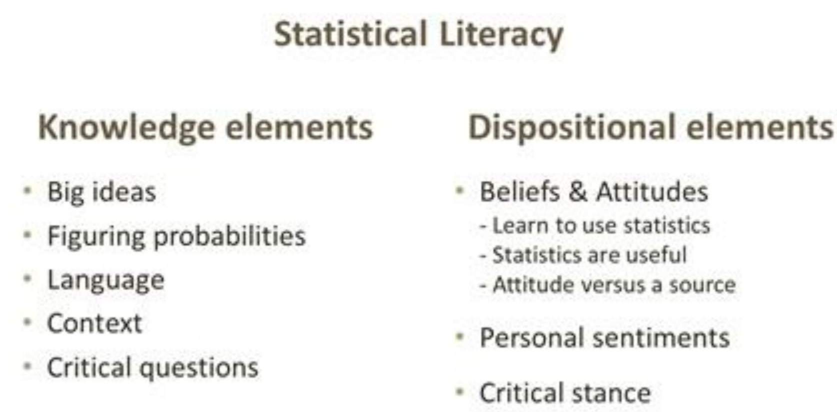

Figure 1. Adapted framework for statistical literacy from Gal (2002).

This framework serves as a theoretical basis, which describes the knowledge, skills and attitudes that are required to be considered statistically literate. The elements of Gal's (1994, 2002, 2005) framework describe the components of a statistical reasoning process by a statisticaly literate person. How these elements are connected to one another in such a reasoning process is more accurately portrayed by figure 2, based on the definition of statistical literacy: "the ability to interpret and critically evaluate outside information involving probabilities, compare this information to one's personal opinion and draw conclusions about the implications of this information" (Gal, 2002; Wallman, 1993; Watson, 2003).

From the framework of Gal, all elements have a place in this scheme. All knowledge elements described by Gal are needed to accurately process the "statistical information". Dispositional elements as "personal sentiments regarding risk and uncertainty" can be regarded as the perception of risk. Concepts like beliefs and attitudes which includes the critical stance are represented as arrows between the different blocks. These concepts drive the search and evaluation of new information and the incorporation of this new information into already present knowledge. Ultimately, they allow for a weighted decision between the old perception and new information.

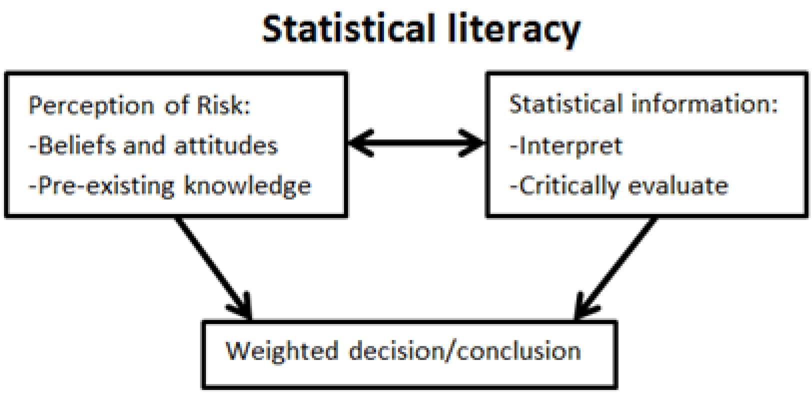

Figure 2: A graphic representation of statistical reasoning processes of a statistically literate citizen, following the definition of statistical literacy, as has been suggested by Gal (2002), Wallman (1993) and Watson (2003). The perception of risk and statistical information influence each other. The dispositional elements describe their effect on each other and how capable a person is to use both to come to a weighted decision or conclusion.

Whether this framework is a correct representation of statistical literacy has not been tested in practice. Also the exact contents of the various building blocks and arrows is not yet well defined. Especially the dispositional elements (arrows in figure 2) are difficult to observe and need to be deduced from someone's reasoning patterns. The level of statistical literacy that is needed to constructively handle information in the way these kinds of concepts present themselves in real life situations, such as in the public media, remains unclear. All these uncertainties stress the importance of providing a practical implementation of this framework by giving an overview of what these elements would entail in a real life situation of a statistically literate citizen. An example of such a difficult real life situation is the SSI of testing for a genetic predisposition. This leads to the main question: What are the essential characteristics of reasoning patterns of statistically literate citizens, when handling a concrete case involving genetic testing??

Method

To create an operationalized definition of statistical literacy in action, a suitable SSI was selected to observe statistical reasoning processes by statistically literate respondents in action. Each respondent was presented with the SSI and asked to think-aloud while reading and interpreting the case and was asked to continue doing that in the following risk-analysis. Think-Aloud Protocols (TAP's) have been used by researchers in multiple fields because of their simplicity and usefulness in establishing thinking patterns (Gal and Garfield, 1997; Garfield and Chance, 2000; Nielsen, Clemmensen, & Yssing, 2002).

After the TAP and risk-analysis a semi-structured interview was conducted on the respondents' views on statistical literacy and its role in their professional practice and reflections on their own performance. A normative task model was used to analyze respondents' statements regarding focal points and weaknesses of the article. Data were analyzed both quantitatively and qualitatively to identify reasoning patterns, difficulties, and participants ideas that could be used to identify the essential knowledge and skills to deal with the SSI at hand.

Materials: the SSI

A first step for this study was to identify a suitable SSI. There is a wide range of SSIs, all with their own characteristics. The possibility of balanced risk-assessment - meaning that the decision to be made involved both emotions and rationale - was most important for this SSI. Therefore, ethical issues (e.g. stem cell research) did not qualify as an SSI, as these primarily evoke ethical rather than statistical considerations. Furthermore, all the risks involved had to be quantifiable, preferably with high levels of certainty, to allow for objective argumentation. Finally, to further address the validity of the issue, the article had to explicitly mention the quantifiable risks and the emotions involved. This ensured the respondents were provided with enough input from both types of elements.

With all these characteristics in mind, the 2013 article "my medical choice" by Angelina Jolie was selected. This newspaper article describes the decision of a double mastectomy following the discovery of a faulty gene (BRCA) which would lead to a severely heightened chance of developing breast- and ovarian cancer at a later stage in a woman's life. Both the decision to test for the faulty gene and the decision to operate were discussed with the respondents, giving two opportunities for a risk-assessment.

The selected article presents an issue many citizins may be confronted with, although the case affects women more personally than men. The selected article was analyzed and adapted to ensure a balanced input of information and to keep the respondents focused on the risk-analysis (see appendix I). Therefore, irrelevant or too biased information was omitted from the case to keep the respondents focused on the risk assessment at hand. The case that was presented to the respondents retrospectively contained one sentence that did not fit these characteristics. This sentence, as well as respondents' statements regarding this sentence, were excluded from analysis.

Respondents

As the focus of this study was on describing the reasoning of statistically literate participants, respondents possessing the releveant knowledge, skills and attitudes required to act as a statistically literate citizens were selected. An additional requirement was that they provide further insight in specific but very different parts of the framework. The respondents were either selected as experts regarding the education of different parts of the framework or as field experts regarding the SSI itself.

Following this reasoning, clinical geneticists (field experts of risk assessment regarding the SSI), biology teachers (subject teachers regarding the SSI) and math teachers were selected to be followed in their approach and thought process when dealing with this SSI. Math teachers were expected to have limited conceptual knowledge about the SSI and would therefore have to discuss the issue in a contextually poor manner. This is in contrast with biology teachers, who were expected to be less numerically skilled and would therefore base their thoughts more on the context. Lastly, the clinical geneticists were expected to already possess all factual knowledge about the subject and the (clinical) practice context and would therefore be most able to critically evaluate the article.

Clinical geneticists interact with lay people on a regular basis and are able to describe the essential features of risk-assessment in their own fields. In this specific case, communicating about this SSI to citizens takes place in two different forms. Not only is there general information provided for large groups of citizens (as would be the case in multiple other SSIs) but also in 1-on-1 contact between experts and citizens in the form of a doctor with his patients.

Three respondents per group were selected and diversity in gender and age-group was ensured. The teachers were employed by different schools to further ensure the diversity of the experts' views. All teachers had at least five years of teaching experience at the time of participating. They teach students that are from the HAVO/VWO level of education and mostly teach students in the three years before graduating high school. More characteristics of all respondents are briefly elaborated upon in the vignettes, which will be explained later in this method section (also see appendix III).

Procedure

Data were collected in single, individual sessions, taking 45 to 75 minutes, depending on the respondent. Respondents were aware that they did participate in a study concerning statistical literacy, but were given no further information. Sessions consisted of a short training for thinking aloud, the TAP itself, a risk analysis and an interview about the participant's vision on the subject, all in immediate succession. Respondents were not given compensation for the time they invested.

Training & TAP

As verbalizing while thinking is not normal practice to most respondents, a basic training of a few minutes was conducted. This has proven to be enough to get respondents to talk quite automatically (Van Someren, Barnard, & Sandberg, 1994). The training consisted of a demonstration by the researcher, a short mathematical problem that had to be solved and a longer text (See appendix VI).

After the training, the respondents were asked to place themselves in the hypothetical situation of deciding to undergo a genetic test. They were asked to read a newspaper article and think aloud while doing so. They were asked specifically to mention important facts and statements, explain what these meant and explain how they influenced their thought processes. Respondents were not given any information regarding the content of the newspaper article before reading it, in order to prevent influencing respondents' thought processes. Respondents were stimulated to talk and were asked to verbalize their thought processes, even on things that were implicit in their thinking patterns. During the training session respondents were encouraged to keep talking when they did not verbalize enough.

Risk analysis

After the TAP, respondents were asked to place themselves in a hypothetical situation, corresponding to the situation of the author: Your mother has just died at age 56 as a result of having breast cancer. Respondents were asked to list the pros and cons regarding genetic testing. They were then asked to weigh these arguments and decide whether to test for the gene or not. Afterwards they were asked to repeat the same type of risk analysis in the case of a positive test result (meaning that they would have tested and would indeed have the gene) to decide whether to operate or not.

The decision whether to test or not was the focal point of this research's analysis, while the operation mainly served as a control. The pilot warranted two different versions of the risk analysis to be used (see appendix IV &V), because clinical geneticists were deemed unable to perform a realistic risk-analysis, as they are trained not to give their opinion and would be more able to mention patient arguments.

Interview

The main goal of the interview (see appendix IV & V) was to gain more insight in the attitudes and beliefs of respondents (the dispositional elements) as well as reflection on their own knowledge elements. Respondents were asked about common misconceptions within their field to allow them to reflect on their own reasoning as experts and to give their views on the flaws in citizens' knowledge and abilities. Thereafter, the experts were asked to elaborate on the specific knowledge, abilities and attitudes that lay people would need to be considered statistically literate in this specific case and thus be able to make informed decisions and form informed opinions. After the experts' own views on these knowledge and skills were discussed, they were asked if certain elements from the statistical framework were not mentioned because they were used implicitly in the experts' reasoning or because they were deemed unimportant.

The nature of the different respondent groups also provided the opportunity to dive deeper into the daily practice of these respondents when encountering elements of this case. Teachers were asked to reflect how well education prepared students for handling this case in real life. Furthermore, they reflected on how their teaching contributed to statistical literacy and what they would want to improve upon. Medical practitioners reflected on how their reasoning patterns compared to those of patients. They were invited to elaborate on the question of how patients should improve, and if they deemed it likely for all patients to have those kinds of knowledge and skills. The data gathered here should be interpreted with more caution, as only three respondents per group were interviewed. Additionally the respondents were not selected with this goal in mind and should not be deemed experts with an impeccable overview of how this case relates to the practice.

Analysis

The aim of the analysis was to identify similarities and differences, both between participants' responses and the framework, and between the different (groups of) respondents. First the focal points and weaknesses of the SSI were determined using a normative task analysis. This resulted in a normative task model and was used as a benchmark against which different reasoning patterns and conclusions were compared. The TAP's, risk-analyses and interviews were transcribed, processed and analyzed, using a quantitative and a qualitative approach. Afterwards, weaknesses from the article that were identified during the normative task analysis were compared to those mentioned by the clinical geneticists, since they are experts on this case. To analyze respondents' understanding, (frequencies of) short statements reflecting a part of the framework were used in combination with a more holistic, interpretive approach. Besides the nature of these elements, using a quantitative analysis in addition to qualitative analysis also provided the opportunity to improve the reliability by triangulation of both data types (Kelle & Buchholtz, 2015).

Normative task model

Analysis of this specific SSI resulted in the selection of three focal points that need to be understood before someone can form a weighted conclusion on whether to test for the presence of the faulty gene or not. These focal points can already be present in prior knowledge or respondents can indicate they want to receive more information about it.

The three focal points consist of 1) knowledge about getting the gene (heredity), 2) knowledge regarding the risks involved with having a certain gene, and lastly 3) knowledge about the costs and benefits of testing. The focal point regarding the risks involved with having a certain gene is divided further into three categories: The lifetime component of the risk, the base rate of 11% versus the 87% of having the gene, and the accuracy of 87% risk. There are numerous places in the article where reasoning patterns involving these concepts could be triggered (see appendix II). If these three focal points are indeed essential all respondents, regarded as statistically literate people, should mention all of these points, without being prompted to do so.

Furthermore, these three focal points should also be interpreted and critically evaluated. Analysis of the article itself suggested two points that could have been elaborated upon more in the article. These are the risks involved with having and the risk of getting the gene. Information about genetic testing in the article is inaccurate, as it calls upon testing without providing further background information regarding the actual risk people have. The origin of these weak points lays in the goal of the article - which was a call to action - and the expertise of the author herself, who is a patient, not a doctor. This is something that will have to be commented upon as well, however one could argue that this falls under literacy in general. If all weak points identified above are accurate, they should be elaborated upon thoroughly in the TAP's of the clinical geneticists, without them being prompted to do so.

Quantitative approach

In the TAP and risk-analysis protocols the (in)correct interpretation and evaluation of the information regarding the three focal points of the SSI were coded using schemes for the knowledge elements of the adapted framework (see table 1). Only the statements from the TAP and risk-analysis were coded, since they involved experts' own reasoning patterns without a question from the interviewer prompting them. The quantitative analysis of respondents' reasoning patterns will provide insight into the occurrences (or lack thereof) of certain elements. These findings could point towards more or less important elements of the adapted framework for statistical literacy. Furthermore, correlations between certain types of elements can be found.

Knowledge elements		
Big Ideas	**I**	Using the important, often abstract, concepts essential when communicating about statistics
Figuring probabilities	**F**	Integrating information, including non-probabilistic information, in order to reach an understanding of probabilistic statements and to generate estimates about the likelihood of events. This means a calculation has taken place (or is proposed), or chances have been compared.
Language	**L**	Switching between different terms (e.g. the difference between "low risk" and "lower risk than", or "low risk" and "1%") and methods (e.g. diagrams and graphs into words) used to communicate about risks.
Context	**C**	The ability to interpret and link probabilistic information to different situations to reach an understanding about the impact or implications of certain probabilities.
Critical questions	**Q**	Questions regarding the truthfulness and completeness of the information. There needs to be an awareness of the writer's purpose, objectivity and reasoning. Also the methodology should be questioned, because the quality of a study's results depends on it (this involves typical problems and biases).
Mistake	**M**	When a statement is made that is incorrect, add this to the coding. E.g.: [MC]
Nothing	**N**	Statements regarding statistical information, without actually interpreting the data or evaluating it (e.g. repeating the sentence)

Table 1: Coding scheme for the knowledge elements of the framework for statistical literacy

The coding scheme first differentiated between statistical and non-statistical statements, after which the statistical statements were coded using the definitions from the framework of statistical literacy (see theoretical framework). Due to the nature of the framework multiple codes could be given to a single statement. The coding instruction (appendix VII) included the definitions as well as examples and non-examples. Two peers were asked to code 82 elements each, 36 from a TAP, 46 from a risk analysis, to determine the inter-rater reliability. Considering the high number of non-statistical statements being scored, the amount of elements used was higher than the $2n^2 = 72$ elements (where n is the number of possible codes) proposed by Cicchetti (1976) for addressing the inter-rater reliability. Afterwards, another peer was asked to critically evaluate the coding.

Qualitative approach

The qualitative data analysis regarding the TAP, risk analysis and interview is used to give insight in “underlying” attitudes, ideas and conceptions that are not evident from an isolated statement. There is a need to interpret statements in the context of the whole protocol. This allows attitudes and beliefs to be properly linked to specific statements. Also different knowledge elements from Gal’s (2002) framework should be considered in relation with the context and personal characteristics of the respondent; the dispositional elements play a key role and knowledge elements cannot be viewed separately from them. Finally, this holistic approach allows the nature of mistakes to be investigated, since they can be caused by faulty knowledge, skills or attitudes.

When all three focal points are mentioned by a respondent, he or she is able to come to a weighted decision. However, this does not imply that the information is interpreted or evaluated correctly. During the TAP and interview the way the respondents perform these actions and how this relates to their prior knowledge and beliefs and attitudes can be investigated using this qualitative approach. This also allows the normative task model to be more accurately used to judge whether the three main weak points, and their origin, are correctly identified and used in the reasoning patterns of the respondents.

Vignettes

With all these goals in mind, one vignette per respondent was created. Vignettes allow for contextual influences on judgment to be examined (Barter & Renold, 1999) and pay attention to the socially situated nature of behavior (Hughes, 1998). Vignettes have a further advantage, as they allow for a quick assessment of the different opinions on the matter and for getting a feeling for the type of person the respondent is. Therefore, the vignettes contained an overview of characteristic reasoning patterns from the TAP together with the risk analysis, an overview of the respondents’ vision and, if needed, a section of remarks regarding the match or mismatch between these two sections. In the creation of the vignettes specific attention was given to accurately portraying the different respondents’ reasoning patterns. Using the normative task model, essential statements regarding the task at hand were included, as well as respondents' emphasis on the different concepts. To ensure this, the translation from transcript to vignette was subjected to peer-review.

Analysis was conducted both on an individual basis as well as on respondents as representatives of their respective groups (mathematics- and biology teachers and clinical geneticists). This allowed for a clearer picture to emerge of what reasoning patterns of people on different sides of the statistical literacy spectrum would look like (e.g. mathematics focus versus context focus). Which part of the case is emphasized by the different groups and what are notable correlations between the respondents of the same group. The importance for educating citizenship mainly lies in the way these groups handle missing certain types of knowledge or skills, while still acting like a statistically literate citizen.

Results

Normative task model analysis

The understanding of three focal points of the SSI was posed as necessary before someone would be able to form a weighted conclusion on whether to test or not. For all three focal points, weaknesses from the article were identified, resulting in a normative task model (see appendix II). These weaknesses are caused by the author's expertise and her goals in the article. The same weaknesses from these focal points have been identified by all three clinical geneticists, while performing their own TAP. A short overview of their remarks will be given here.

The first weakness considers the real risk of having a faulty gene. Faulty genes give an increased lifetime risk compared to the normal situation (base risk). While some develop the condition early in their lives, some might not develop it at all. Because of these issues, geneticists cannot pinpoint the exact risk of getting breast cancer when you have the gene. Therefore they give a range (60%-80% risk) instead of an actual number (87%) like the article mentions.

The second weakness is something that is not mentioned in the article, even though it is very important to consider when making the decision: Not only the heredity of the gene should be mentioned, but also how this affects your family since they could have the gene as well. Notable elaborations on this problem given by geneticists are the understanding of Mendellian genetics and the 50% risk of the gene being transferred to your children, including the fact that this 50% chance is not changed by prior events. This was supplemented with the often present misconception in their patients:

That sons are not important when considering the implications of having the gene. However, sons do inherit the gene, although they rarely express it, and can pass it on to their children.

Finally, the inaccurate and therefore most important weakness is the call for testing. A good point in the article is the observation that only a fraction of people with breast cancer has the gene. However, the link between 458.000 dying from breast cancer and concluding that testing for the gene is imperative is wrong, because most of those cases are not caused by the gene. The geneticists expect citizens to be critical towards this call for testing. Further additions to this problem are addressed by geneticists saying: "A 56-year old mother with breast cancer does not make me think of something hereditary" meaning that the case Angelina Jolie describes would not lead to an indication for testing for the gene by Dutch hospital guidelines. Furthermore the discussion depicted here focusses too much on the operating versus not operating, in stead of mentioning screening as a preventative measurement.

Quantitative analysis

The first (quantitative) approach to reach a better understanding of different reasoning patterns of statistically literate respondents was to characterize these reasoning patterns by coding them for the elements of the statistical framework. Missing elements or frequently occurring elements would be able to provide information about the importance of these different elements for statistical literacy. The inter-rater reliability of the coding scheme was very low, although no kappa could be calculated, since statements made by respondents were able to receive multiple codes. In the TAP, from 16 statistical statements, only 1 was fully agreed upon (meaning all codes given to the statement matched). As an example with multiple codes, this statement was made by W.B. after reading the following section from "My medical choice":

> "I wanted to write this to tell other women that the decision to have a mastectomy was not easy. But it is one I am very happy that I made. My chances of developing breast cancer have dropped from 87 percent to under 5 percent"

> "Well, she has done this and her chances of developing breast cancer have dropped from 87 to under 5 percent. This sounds like less than the average woman. That is quite something." (W.B.)

In the respondent's reasoning pattern, the first statement is not scored, since it is considered paraphrasing Angelina Jolie. The second statement, however, does show statistical reasoning. Comparing 5 percent to the average woman and concluding it is less, is an example of figuring probabilities. Translating 5 percent to less than average is an example of understanding the language element. Finally, showing appreciation for the implication of the risk going down to 5 percent is an example of the context element.

The peer-review in which the coding was already present improved agreement up to 6 out of 16 elements. With another 5 statements partially agreed upon, there was still disagreement in 5 cases. These results imply that the framework is not a suitable tool to score statistically literate behavior. The characteristics of the framework itself provide an explanation as to why the framework does not work as a scoring tool. First of all the framework only partially describes observable behavior. Multiple characteristics of statistically literate reasoning are not visible, for example: "Going from 87% to 5% lets you feel good about that decision, but 5% is still a reasonable risk. (M.A.)". It is impossible to infer from this statement alone if the concept of base risk has been understood. 5% is considered a very low risk, but the origin of this mistake could be from different areas: a faulty pre-existing knowledge (unawareness that it is low), a misunderstanding of 5% as a lifetime risk or possibly other causes. The only way to get an idea of the level of understanding is by using the context and other reasoning patterns made and derive the way this statement was meant from those. This implies that the qualitative method used in this research is much more suited to answer the main research question.

With these reliability issues in mind, it is still possible to use the quantitative data to guide qualitative analysis in the right direction. The scoring table (see table 2) shows a lack of occurrences of big ideas, followed by low counts for the language elements. Furthermore, the language component is used only sporadically by clinical geneticists in comparison with the other groups. Context is used by all respondent groups, although qualitative analysis has to confirm whether these statements are equally complex and/or accurate. Lastly, the most critical questions during the think aloud protocol are asked by clinical geneticists, whereas during the risk-analysis this is done by biologists.

	TI	RI	TF	RF	TL	RL	TC	RC	TQ	RQ	TN	RN
M.B.	4	2	7*	9	4	5	11*	30*	7	7	20	13
M.A.	1	1	2**	10*	5*	6	6	17	2	8	4	32
M.R.	2	4	5	6	5*	6	5	9**	9	5	19	30
B.G.	2	2	4	3**	1**	5	6	17	2**	5	13	38
B.M.	0	2	4	11*	2	7*	6	14	10	14*	7	23
B.E.	1	2	3	7	4	7*	6	15	8	9*	18	36
C.M.	3	3	6*	6	2	2	5	20*	12*	9*	8	20
C.J.	2	4	4	8	1**	1**	3**	17	14*	1**	10	27
C.T.	1		4		1**		6		8		3	

Table 2. Number of occurrences per knowledge element of the statistical framework. All respondents are visible on the left. Respondent codes correspond with their vignettes (appendix III). The first letter represent their group: biology teacher (B), a math teacher (M) or a clinical geneticist (C). The second letter represent the specific respondent. The column codes refer towards when the respondent reasoned with a certain element (T = during Think Aloud Protocol, R = during risk-analysis) and which element is mentioned (I = big Ideas, F = Figuring probabilities, L = Language, C = Context, Q = critical Questions, N = non-statistical element). Most occurrences in a column are marked with a single asterisk, least occurrences are marked with two asterisks. Data from the risk-analysis of C.T. is not available.

Qualitative analysis

This section will contain the details about the qualitative analysis of the data. This analysis tries to give insight in underlying attitudes, ideas and conceptions respondents have. It will paint a picture of different reasoning patterns and different levels of understanding that respondents demonstrate while handling this concrete case. Given its nature, presentation of the data is descriptive. All quotations used to support the interpretations of the data are followed by a code in order to refer to the respondent. The first letter of the code indicates this respondent being a biology teacher (B), a math teacher (M) or a clinical geneticist (C). The second letter represents the specific respondent. Codes also correspond to the vignettes (see the complete set of vignettes in appendix III). The example below shows how a vignette is capable of adding value to a statement or in this case, lack of a statement. The think aloud protocol and risk-analysis section of the Vignette of a biologist (B.G.) can be seen in box 1.

In this case a statement by the respondent regarding the reliability of the 87% risk of getting cancer is missing. This could have different reasons: The respondent could think this 87% is a legitimate estimate, or it can be seen as a lack of critical attitude on the part of the respondent. The vignette shows us in the last statement he makes: “I do not read this article in a scientific way, to look for misleading information. I read this story from the viewpoint of a woman in such a situation", which shows an even different approach to this article: B.G. can be critical, but chooses not to, because he feels like the author is not suited to give medical information.

> Only a fraction of breast cancers are caused by BRCA-1, or Breast Cancer Gene 1, which could be prevalent in different fractions in different populations around the world. A 65% chance in life to get breast cancer is a gradually increasing chance over a lifetime. Although I do not know how to imagine 87%. This is a lifetime risk, but what does that mean for the chances of developing it in the next year? That would help me in my decision. It does feel like such an unattractive risk, that I would want to know if I had the gene, if I was younger.
>
> 5% is kind of the percentage for people that do not have a genetic predisposition. And although there will be a chance the operation goes wrong, it will be smaller than the risk of developing breast cancer. Because of this risk, I would prefer other methods like a medicine to block the gene, if that was available. Let doctors tell you the consequences and risks of treatment and non-treatment. People can also be so afraid of the risk and consequences that they burry their heads in the sand and don't go out for help. I do not read this article in a scientific way, to look for misleading information. I read this story from the viewpoint of a woman in such a situation.

Box 1, Think aloud protocol and risk-analysis taken from the vignette of B.G.

Not only the TAP and risk analysis can be used to deduce pre-existing knowledge and beliefs and attitudes, but also the vision of a respondent is important to better grasp this part of a persons' reasoning patterns. The vision of a respondent will also be used to draw implications from the conclusions. The last part of the vignette is comprised of remarks, which highlight important differences between someone's vision and their TAP, or between group members.

In the following section all elements of statistical literacy will be discussed after analysis of the vignettes of all 9 respondents separately, as well as in groups of their various expertises. Similarities and discrepancies will be used to judge completeness and more or less important features of an element. In this framework the knowledge elements describe the way statistical information is being interpreted and evaluated (statistical information, figure 3). These elements are visible in statements made by the respondents, although these statements alone do not paint the whole picture. For example, when a mistake is made, this could have been caused by multiple factors. In each knowledge element, attention is given to the origin of these mistakes.

The way the respondents handle the statistical information is impacted by everything they know and feel about this subject before they come into contact with the information in this SSI. The pre-existing knowledge and beliefs and attitudes also form the perception of risk the respondents have before reading the article (perception of risk, figure 3). Because the pre-existing knowledge and beliefs and attitudes are different in all respondents, a different way to handle outside statistical information and a different perception of risk is to be expected. Also the influence of perception of risk and statistical information on each other (double arrow, figure 3) as well as their influence towards a weighted conclusion or discussion (weighted decision/conclusion, figure 3) are expected to differ between respondents.

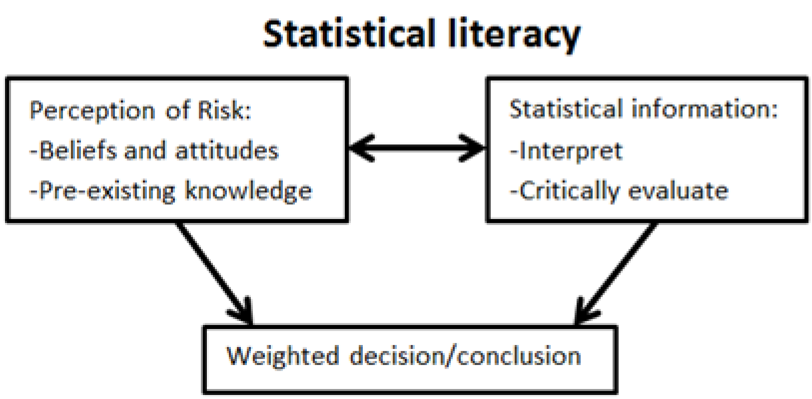

Figure 3: A graphic representation of statistical reasoning processes of a statistically literate citizen, following the definition of statistical literacy, as has been suggested by Gal (2002), Wallman (1993) and Watson (2003). The perception of risk and statistical information influence each other. The dispositional elements describe their effect on each other and how capable a person is to use both to come to a weighted decision or conclusion.

Statistical Information

Big ideas

Respondents do not often mention big ideas. Most noteworthy are the ideas of randomness, independence and average, which are directly mentioned by respondents. For example: *"A random 50% chance of inheriting genes is actually 50% and is not changed by prior events (C.M.)"*. *"This 87% is a high percentage on the basis of just one gene and must be an average itself, or did they research all of her genes?"* (B.E.). More often concepts are used implicitly, for example variation: *"87% risk is different for* *every woman"* (M.R.) and independence: *"The chances of breast and ovarian cancer need to be looked at separately"* (M.B.).

Most respondents do not think the big ideas are very important, and those that do feel they are important, do not think you need to talk about the different concepts for either biology or in a geneticists office. *"You don't need to know statistical concepts to use them"* (B.M.). *"Concepts from statistics will play a role in the story, however you shouldn't use those terms in a talk with the patient"* (C.J.). Even though respondents do not think the big ideas are very important, they all demonstrate a thorough understanding of these concepts underly statistical reasoning. Although respondents made multiple errors based on wrong presumptions and numbers, these could never be attributed to a lack of skills or misconceptions concerning the big ideas. However, generalization should be done with caution, since big ideas are not often visible when talking about risks.

Language

The understanding of different terms used to communicate about risks is most visible when respondents correctly switch between one form of representation to another, mostly from percentages to words. They do this in a natural way, almost unaware of actually doing this in the same sentence: *"Well, the risk going from 87 to 5% is a very big drop, of course"* (M.B.), or as a follow up from the percentage 87%: *"I would, if the risks are this high, undergo surgery"* (B.G.)

All mathematics teachers stress the language component as a prerequisite for a good understanding of the situation. *"Language and critical questions are the most important ones. You need to interpret the numbers, graphs, methods of representation, do they accurately represent what I want to know?"* (M.A.). Important to note is that, like in this quote, language is often mentioned in combination with critical questions. However it appears difficult to fully grasp the difference between language (reading a graph) and communication (reading the intention of the author between the lines; part of critical questions). This difference is elaborated upon quite elegantly by a math teacher:

> "The use of language is most important, because this is how the information is transferred to the reader. Language is never entirely rational and may be received differently than aimed by the author. You have to ask critical questions about the language that is used. Language is never rational; something comes across in a certain manner by the language you use. It also stresses

certain matters. Language is also not the same as communicating about something. You can understand a graph or text, but not the actual communication, you need more for that" (M.B.)

This shows how language can be a very important way to influence how data reaches the recipient and should be picked up by statistically literate citizens in the critical evaluation of the information.

Figuring probabilities and context: Lifetime risks

The calculations shown by the respondents all relate to one of the three main statistical elements described in the mental model. This implies that every calculation is embedded in a context and this influences the outcome of the situation. This is the reason the three elements will be looked upon separately.

The Lifetime component of the risk of cancer is not mentioned by M.R., M.B., and B.M.. Looking at the Vignettes of these respondents, M.R. and B.M. both point out they would like to monitor the disease before opting for surgery, which could mean they see 87% as a lifetime risk. M.A. and B.E. show a good representation of the concept of lifetime risk, however they do not apply this correctly, e.g.:

"87% is that for life? If this is per year then you can be sure you will not be around after 10 years. If it is not, the percentage will grow over time, so I want to know what it would mean for someone 10 years older or younger." (M.A.)

An improvement on this last example is the ability to form a representation of a lifetime risk in your head.This is considered to be really difficult by the respondents (C.J., C.M. and B.G.), that did manage to accurately identify and apply the lifetime risk:

"A 65% chance in life to get breast cancer is a gradually increasing chance over a lifetime. Although I do not know how to imagine 87%. This is a lifetime risk, but what does that mean for the chances of developing it in the next year?" (B.G.)

The last step is to calculate (or estimate) the probability of someone developing cancer when you consider their age. Only one respondent shows confidence in his ability to do this:

"When you are 60, you have lived 60 years without developing breast cancer and your risk is lowered to 20%." (C.T.)

Figuring probabilities and context: Base Risks

The base risk of breast cancer in woman without the gene mutation is not mentioned by C.M., although it is not clear why she did not mention this. The remainder of the respondents all used the concept of a base risk in their reasoning patterns, all in a correct way. However, not all respondents (M.A., M.R. and B.M.) reached the correct answer and what was inferred from this was not always correct. This is illustrated by the following example, where M.R. (unknowingly) comes to the conclusion that she would want her breasts removed, while not having the gene, because the base rate is actually around 12.5%:

> *"A faulty gene leads to breast cancer, but there are other factors too, because this is only a fraction. For me to keep walking around with a ticking time bomb, the chance would have to be smaller than 5%."* (M.R.)

The problem here lies not in the understanding of base risks, but in the contextual information about the base risk of breast cancer. The way respondents build an argumentation with base risks, it is highly likely they would not reach the same conclusions, had the base-risk of breast cancer been mentioned in the article. Some respondents identify not knowing the base risk themselves, e.g.: *"I would like to know … base risk of breast cancer" (M.B.).* Ultimately only two geneticists, C.J and C.T., were completely accurate and confident in their statements.

Figuring Probabilities and Context: Heredity

Familiarity with the non-statistical concepts involved in this case is about two important biological concepts: Cancer and heredity. All respondents expect knowledge about the effects of cancer (not its mechanisms!) from all citizens, however a familiarity with the chances of actually getting cancer yourself is not expected (see base risks). Respondents come to the conclusion that that actual knowledge about genetics and heredity is not important to make the decision about whether or not to take the test and to operate. This decision can be reached simply by an understanding of chances and implications of risks: "*You can just make that decision by the numbers of the risks"* (M.A.)

A familiarity with heredity is present in all mathematicians, although numbers of Mendelian genetics are not, e.g.: "*I would like to know… the risk of inheriting the gene from the mother"* (M.B.). Not knowing how Mendelian genetics work is also reported to regularly occur in patients, e.g.:

> *"Patients could say: "I look like my mother, so I have more genes in common with her, than with my father." However, a random 50% chance is actually 50% and is not changed by prior events."* (C.M.)

Although biologists do grasp the concept of Mendelian genetics, an important part of the problem is often overlooked. This encompasses the need to look further than yourself and realize the consequences this problem will have for your family. Because not only you might get cancer, but your family could also be at risk. They might not even have wanted to know they have this risk! All clinical geneticists, M.A. and B.M. mention this problem, e.g.:

> *"Not only she, but also the children are at risk of the gene, this is not mentioned in the entire article"* (C.T.)

> *"When you test for results for children, you immediately also have a result for the parents. Same goes for identical twins."* (C.M.)

A point made by all clinical geneticists is that a low conceptual understanding indeed can be overcome and therefore does not influence the personal decision much, but it does severely hamper people's abilities to take into account the effects that both the situation and the decision will have on others.

> *"Although theoretically everything gets explained in a consultation, it's a lot of information about a complicated decision"* (C.M.)

> *"It is much easier to talk about the decision itself, because we don't have to inform them…. if you already know a lot, you have more room for taking in the whole story"* (C.T.).

When focusing more on the impact of specific chances, context starts to play an even bigger role: *"Terminology of the context and estimating the impact of certain chances are most important in the patient's situation"* (C.M.). And the confidence of respondents in their understanding goes down: "*It is difficult to understand the impact or meaning of a certain chance*" (B.G.).

As you understand the context better, you are able to make more complicated calculations: *"Your parents have a gene, what would be the probabilities of you getting the gene and of you expressing the gene?"*(B.G.)

Critical questions regarding the context: Is the risk of developing cancer exactly 87%?

When reading the section about 87% risk on breast cancer, a critical question can be posed regarding how this number was attained. Three respondents (M.A., M.B. and B.G.) did not comment on the 87% at all, whereas one respondent only tried to make sense of the 87%: *"It must mean she has genes in common with women, from whom 87% developed breast cancer."* (M.R.). The biologist not commenting on the 87% specifically stated later that: *"I don't read this article trying to comment on its numbers… I would not take medical advice from Angelina Jolie"* (B.G.) as was already demonstrated in the example of vignette use above.

The other two biologists do question the 87%, although they are not really certain of their own knowledge on this subject, e.g.: *"The risk is different for every woman. Then 87% is very specific"* (B.M.). This statement shows a feeling of something being wrong, however, it is not called out directly.

Finally the Clinical geneticists do call Angelina Jolie out on providing faulty information, e.g.: *"87% and 50% suggest some kind of accuracy that we do not have. We use a range of 60-80% and 30-60%."* (C.T.).

Critical questions regarding the context or probabilities: Is genetic testing imperative?

After reading the article every person at the very least should ask themselves the question if the statement regarding genetic testing is justified. Without other information or correct interpretation of this statement, one could infer from this that everyone should let themselves get tested for this gene. Whether intended or not, according to the clinical geneticists, hospitals received almost double the amount of inquiries about such tests in the months following this article.

B.G. did not mention anything related to this statement, although from his Vignette it can be inferred he did not read this article with the intention of posing critical questions, because he only read the article to learn about a patient's experience. B.E. also did not mention things related to this statement, although he does make the general remark that "When you thoroughly analyze this article you come to the conclusion you need much more information for your own decision, although it is good she tells people to consult with medical experts". All other respondents dispute the claim directly.

This dispute is performed in one of three ways. First of all, the three clinical geneticists proclaim the statement to be faulty. This is done with a lot of confidence, because of certain hospital guidelines the geneticists are used to following, e.g.:

> *"She acts like everyone can just do a test, but there has to be an indication according to our guidelines"* (C.M.)

And even the premise of Angelina Jolie's own genetic test is disputed by one clinical geneticist:

> *"A mother with breast cancer at 56 does not make me think of something hereditary."* (C.T.)

B.M. chooses a more context driven approach to this situation. She has a feeling for the chances someone could have on developing breast cancer by a genetic mutation. She realizes the mother having breast cancer while being 56 years of age is not enough to test for the gene. Also when your mother does not have the gene, you could still have an indication to test:

> *"For risks of testing not only my mother is of importance, but also other female family members. Angelina Jolie should not end with a call for testing, which is irrelevant and misleading without the proper background information"* (B.M.)

Mathematicians choose for an entirely different way to dispute the call for testing. They are able to use the contextual information that was given in the article (the gene is present in a fraction of all breast cancers, 458.000 people die from breast cancer), to suggest a way to calculate whether a test is actually warranted for the entire population.

> *"She calls for testing, but I would have wanted to know the amount of persons out of 458.000 we might have saved with early testing and the false positives and false negatives"* (M.B.)

> *"A faulty gene leads to breast cancer, but there are other factors too, because this is only a fraction. Almost half a million deaths are not from the wrong gene, so you cannot prevent them all"* (M.R.).

This shows a thorough understanding of the methodology behind proving the relevance of testing and vaccination programs in general.

Critical Questions: Origin of the weak points

All respondents elaborate with multiple sentences about the goal of this article. Also the quality of the source(Angelina Jolie talking about a medical decision) is subject to multiple critical questions. It is the view of all respondents that people should be able to distill the goal and assess the quality of the article. Questions regarding the quality and goal of the writer are made without remarks about the statistical information, e.g.:

> *"You have to understand that A.J. might not be the best source for this information, and she is definitely not the only source or a perfect source. She has a goal with her article. People should not base their decision on one source, not from friends, not from the internet"* (M.R.)

> *"It is important that everybody is able to get the facts out of a story and reflect: do I agree with the decision made because of those or is the story guiding me in a certain direction. The viewpoint of the author might not be the whole truth"* (M.B.).

Noteworthy is that respondents do value her highly as an experience expert. Which means the quality of the source is viewed differently for the type of information that is given by the writer in relation to his or her expertise. Furthermore the importance of consulting multiple sources is stressed. Not only for information on the facts but also about experiences in dealing with this situation.

Looking at the statistical information the three respondent groups differ considerably regarding the amount, timing and type of critical questions asked. First of all, the clinical geneticists are able to pose most critical questions during reading. Their critical questions are not so much questions, as they are critical remarks at the information given, e.g. *"87% and 50% suggest some kind of accuracy that we do not have"* (C.T.) and *"like everyone can just do a blood test, we don't appreciate this very much"* (C.J.). Biologists have a different tone and timing of the critical questions. They need more attention for the article and ask most critical questions when they are prompted, but not in their TAP. From their pre-existing knowledge they draw the conclusion that something is not right, however, they have less confidence in their own knowledge and pose this more as a question: "*This 87% is a high percentage on the basis of just one gene and must be an average itself, or did they research all of her genes? 87% to 5% is also a lot, how do they get these numbers?"* (B.E.). Lastly the mathematicians place considerably less critical questions, especially about statistical information given in the article (e.g. none about the 87%). Instead of questions, they mostly mention pieces of information they are lacking in order to accurately judge the given information, e.g.: "*I would like to know the risks of operation, the risk of inheriting the gene from the mother, the base risk of breast cancer, the amount of persons that we might be able to save with early testing and the false positives and false negatives"* (M.B.).

An unexpected situation occurred during the interview parts with the clinical geneticists, in which the frameworks were being discussed (see appendix V). Clinical geneticists were asked: “What is in your opinion the most important part of the framework?”. The following quotes grasp the situation: *“Being able to ask your important questions, as well as daring to pose them”* (C.M.), *“Critical attitude is important. That you pose questions if you don’t understand something“* (C.T.). One geneticist went even further: *“Posing critical questions is something only educated people will do, but they are not needed in general healthcare. It is also a negative term I think, an open attitude is more positive: you have to be able to receive information and ask questions about what you want to know”* (C.J.). This demonstrates a mismatch between the behavior of clinical geneticists and their vision on the subject. Although all adopted a critical stance, it is not expected from the patients.

The perception of risk

The perception of risk is formed by the feeling respondents have with a certain chance combined with the feeling they have with a certain implication. Both are influenced by pre-existing knowledge and beliefs and attitudes, as well as by processing new information. This means the perception of risk can change after respondents have read this article. In this section both elements underlying the perception of risk will be discussed. As respondents were selected from different backgrounds, a clear distinction in pre-existing knowledge was expected. However, this did not necessarily imply that their beliefs and attitudes would be different.

Pre-existing knowledge

The influence of pre-existing knowledge on the perception of risk is mostly visible in the comments respondents make regarding the base-risk and the lifetime risk of breast cancer. From statements like “*For me to keep walking around with a ticking time bomb, the chance would have to be smaller than 5%.”* (M.R.) and “*5% risk after the operation still seems like a whole lot”* (B.E.), it can be concluded that the perception of risk from this respondent is not in agreement with the actual risk. This is heavily influenced by emotions regarding this risk and often leads to falsely giving too much attention to small risks. Much focus is on the implications of developing breast cancer, whereas its very low probability is misinterpreted or neglected. The main reason for this mistake is an unfamiliarity with the base risk of developing breast cancer - which is 2.5 times higher than 5% - combined with a difficulty of understanding lifetime risks and comparing this to the risk of dying from other causes (a base risk of dying in general).

This problem also occurs when talking about the 87% lifetime risk. The impact of this risk is often overestimated, because people do not realize getting breast cancer is often treatable, or do not understand the impact of the lifetime component of this 87% risk. In our respondents, the treatability was understood quite well, whereas the lifetime component was completely understood by only one respondent. This perception of risk should change after talking to a geneticist, however this does not always happen: *"When taking drastic decisions, 60-80% feeling as 100% is a fatalistic feeling, which should be talked about with a psychologist."* (C.J.).

Beliefs and Attitudes: Emotions

The belief that statistics can help you in your reasoning is at the basis of every reasoning pattern that uses outside statistical information in order to come to a weighted decision. This statement seems most logical and redundant but there are gradations of importance people might place in using statistical facts versus emotions in their reasoning. Some people might just go by gut feeling without informing themselves at all. Respondents give much importance to this attitude: *"Statistics can help you in these problems is the most important one, because this is the basis"* (M.R.). It would even be preferred if everyone would be able to just use statistics to base their decision on and only later think about what it would mean for them, as is illustrated by B.G.: *"People should first weigh cold data to come to a conclusion and then discuss this with their surroundings in order to weigh in emotional arguments"*. In this simulation, emotions are talked about, but not really present as they would be in real life. Respondents agree that this would be an ideal situation, but that it cannot occur in the real world, since emotions always play a big role.

To further stress the importance of emotions, it is important to realize that a person dealing with this situation probably just had a family member diagnosed with cancer; someone who is trying to beat the disease or might have lost this battle already. As has also been touched upon in the section about the perception of risk, the emotions change the perception of the height of a certain risk. Not only because a family member did develop cancer, but also because of a better understanding of the emotional side of the implications: *"If you have already witnessed the effects of cancer on your mother, your decision will be impacted"* (B.E.). Someone cannot be expected to think completely rationally about this situation. This is the main reason respondents do not think it is possible to shut out emotions, but there should be an awareness of their effects: *"Although reaching a total understanding of the impact of emotions on a chance or risk is impossible, already having an idea of the impact of emotions on risk-perception is a good start"* (B.G.). Furthermore, people should try to lower the effects of emotions by: *"Giving yourself the time to think about it and not go with your first thought, being able to weigh in new information about the problem"* (K.M.). Note that this statement reflects how we would like people to handle SSIs.

Beliefs and Attitudes: Changes over time

Although respondents generally admit they never thought about this before, they think the statement about risk-averse or risk-taking behavior is a very notable one.

> "*I would not want to know the risk on everything that could go wrong, but you need to define for yourself with how much risk do you want to live*" (M.A.).

Some respondents also make the link with a changing perception of risk over time, e.g.:

> *"Personal attitudes versus risk are very important. What a risk means to you and which action you take. Your perception of risk does not need to be a static thing. This can change over the course of time. "*(C.M.).

This changing perception of risk over time is more directed towards someone's beliefs and stance in life and are more long-term influences on risk perception than emotions. This difference in beliefs and its causes surfaced when the teachers were confronted with the hypothetical situation of having a mother, who was diagnosed with breast cancer, just like in the article. Three out of four relatively young respondents (all except M.B.) wanted to know if they had the gene, while both older respondents (M.A. and B.G.) were much more reserved, e.g.:

> "*Age is important in this problem. When they are younger, more people depend on you and the pay-off is bigger. Now it only causes dilemmas that I don't want to deal with while I have no symptoms"* (B.G.).

Beliefs and Attitudes: Consulting outside sources

The belief and attitude that you are capable of learning and using statistics, as has been suggested by Gal (2002), stands or falls with people being able to admit they need help and asking for it. It is difficult for teachers and geneticists to estimate the understanding of other people if they do not come forward with their questions. This is mainly caused by a feeling of shame for not understanding, while there should be none, e.g.: *"During consultations patients might say they understand, but do that because they might not want to admit they don't understand"* (C.M.) and "*People think this is difficult, but do not show this, because they would feel stupid"* (C.T.). Although these experts are trained to explain people things they are not expected to know yet, many people do not ask for help. This also applies to going to the doctor with your concerns in the first place and not burying your head in the sand for your problems.

While it might be difficult to admit you lack knowledge and need help, it might be even more difficult to doubt your own knowledge and interpretations. *"Ask for someone to reason with you and check your interpretations, because you are not infallible and you are influenced by personal experiences"* (B.E.). Furthermore it is expected from citizens that they also reflect on their decision, which is easier to do when you talk to others about it. *"Talk to your surroundings and take a decision that you and others around you feel good about"* (B.G.). This would not only lead to a better understanding of the situation, but also would improve coping with the situation. Not only friends and family should be considered, but also people who are in the same situation can make you understand more and cope better with this situation.

Conclusions

This research set out to answer the main question: What are the essential characteristics of reasoning patterns of statistically literate citizens, when handling a concrete case involving genetic testing? Five knowledge elements and a cluster of beliefs and attitudes were proposed as jointly essential for statistical literacy (see figure 1 & 2). This theoretical basis was used to analyze different reasoning patterns in statistically literate citizens. Overall conclusions from the analysis will be outlined here.

The quantative method using the framework as a coding scheme proved unreliable, however it was able to steer the qualitative research in the right direction. The knowledge elements where not all equally present in respondents’ reasoning patterns. The small number of times big ideas were used, they were often used implicitly in reasoning patterns of the respondents. The absence of using big ideas is not surprising, when looking at the way the respondents talk about what they think is actually needed for statistical literacy. Although all knowledge elements were deemed necessary for their own reasoning, respondents attributed a low priority to understanding big ideas and rarely use them in biology classes and virtually never in the geneticists’ offices.

Just like big ideas, the language component of statistical literacy is also often used implicitly and (seemingly) effortlessly by respondents. Unlike big ideas, the language component is stressed as a prerequisite for a good understanding, although the difference between language and communication seems to be difficult to understand for some respondents. The implicit use of big ideas and language components could point to knowledge-encapsulation, which might lead respondents to forget how important those concepts were to reach the amount of understanding they currently have.

The reasoning of statistically literate respondents is not perfect and they do make mistakes. For example, faults arise from not knowing the actual base risk of breast cancer. Therefore their perception of risk is off (discussed later). If the base risk was included in the text, or researched by the respondent, it is unlikely that they would have made this mistake. This is in line with the view that you don’t need to do the research yourself and also that you only have to be able to comprehend probabilities that are being explained to you, not perform calculations yourself.

Lifetime risks were more difficult to understand than base risks. Five teachers were unable to accurately detect or apply the concept. Geneticists were all able to, but expressed their difficulty with the concept, and all mentioned their patients had an even harder time grasping this. If this is difficult for all respondents, we cannot expect it from the general public. This, again, is in line with the view of being able to comprehend someone else’s explanations to the calculations, but not performing them yourself.

Although heredity is only very basically understood by math teachers, this does not seem to undermine their ability to draw a conclusion regarding their own decision. Personal decisions can be made purely based on chances and implications regarding those risks. This means, however, that the risk perception of these chances needs to be accurate. Furthermore, geneticists indicate that unfamiliarity with the context hampers your ability to relate your situation correctly to your family and the implication it has on them. However, in both teacher groups there was a similar realization of this implication. Not realizing this implication does not immediately imply that one would not be able to understand the impact on the family.

Although all elements were considered jointly necessary, the respondents implied a more hierarchical structure of these elements: *"The first four knowledge aspects are completely intertwined. You need them all for a good understanding. Critical reasoning can only be reached when you understand all aspects of statistics"* (B.G.). Multiple respondents place critical question as the most important and most difficult one to reach. This is further supported by the manner in which critical questions were posed. Critical questions always occurred together with another knowledge element if the question regards statistics (i.e. not doubting the quality of the source). Context and the representation of information stand at the basis of critical questions, so much that it can be argued that critical reasoning can only be reached when you understand all aspects of statistics. This means critical questions should be viewed as a higher order knowledge element

With a highly critical attitude, every number in the text warrants a question regarding its reliability and methodology of construction. Without pre-existing context knowledge it becomes increasingly difficult to pose critical questions about statistical information, evidenced by zero critical remarks by mathematicians regarding the 87% risk of breast cancer. The more contextual knowledge and familiarity with the situation a person has, the more inclined one is to pose critical questions and the more confidence one shows in attacking a claim or statement. Where biologists merely question the 87%, the geneticists actually shoot down this number. Also the timing of the critical questions is dependent on the pre-existing knowledge.For example, geneticists are able to question a statement the second they read it, while biologists more often comment on the statement when they are asked about it afterwards. The fact that this number is not criticized by all respondents does agree with the view of most respondents that an expert should be consulted for this information, instead of Angelina Jolie, whose expertise on this subject is called into question by all respondents. They suggest to go out and consult multiple sources and always question their quality and objectivity. The goal and subjective nature of the article are recognized by all respondents. The respondents show various ways of tackling a statement: without going into the numbers, context knowledge can be used to reach an opinion on whether testing is a viable decision for you. Without going into the context, mathematicians demonstrate that by a thorough understanding of methodology, they are also able to reach a correct conclusion about genetic testing. This might even be considered a higher form of statistical literacy.

Pre-existing knowledge and beliefs and attitudes contribute to the perception of risk. The perception of risk changes when reading new statistical information. When the perception of risk is too high or too low, numerous variables could be playing a role. Firstly, it could be related to faulty pre-existing knowledge, something that could be fixed by consulting the right expert or outside information. Secondly, it could be related to a lack of understanding of the statistical information given, which points towards statistical illiteracy. This could be remedied by education, although it might prove very difficult to attain for everybody. Thirdly, emotions will always play a role in SSIs and even more so in the case when someone closeby might have been diagnosed with cancer. Decisions however, should be taken with as little influence of emotions as possible and some time may have to pass before this is possible. Beliefs and attitudes further influence the perception of risk, whether it is from a stance in life or having dealt with the situation before. Both emotions and beliefs and attitudes could influence the way risk is perceived. The actual risk is calculated by chance times impact, however impact usually gets too much attention. Emotions will always play a role, however, being aware of its influence on the perceived impact already goes a long way. Finally, while it might be difficult to admit your perception of risk could be off, it is imperative to doubt your own knowledge and your own perception and discuss these with outside sources (e.g. a general practitioner) and your surroundings.

In summary, pre-existing knowledge and beliefs and attitudes contribute to the perception of risk, which changes when acquiring new statistical information and is influenced by emotions. All knowledge elements were used for the interpretation and critical evaluation of this stastitical information. In this critical evaluation, attention should be given to the way information is communicated. Lacking context knowledge or having lower skills in figuring probabilities did not hamper respondents from reaching the conclusion that the call for genetic testing was unjustified. Different ways to reach this conclusion about the newspaper article were shown. Although they reach the same conclusions, the more context knowledge and familiarity respondents had with the SSI at hand, the more confident respondents were in their own vision and the more they doubt the article at hand. This substantially lowered the influence the statistical information had on the perception of risk.

Discussion

Limitations

The reasoning patterns that were shown by statistically literate citizens, when handling a concrete case based on genetics give a better understanding of the skills and attitudes a statistically literate citizen has, as well as more insight into its education. The more abstract definition of statistical literacy has been operationalized, however this has only been done for one specific case. Caution must be taken before transferring this operationalized definition to other SSIs or less cognitively demanding tasks involving statistics. Statistical literacy is a much broader subject and more research will have to be done into other subjects. Gal (2000) proposed a total of ten different fields where statistics are used by citizens which all have to be researched to get a complete image of statistical literacy in the practice of everyday life.

The case this research has focused upon was chosen by examining four leading characteristics of statistically literate thinking. However, no illustrations of diagrams or graphs were shown in the newspaper article. Although these illustrations where absent, the majority of respondents noted language as one of the most important elements. This shows the importance of understanding the language in which statistics are communicated and plays a big role in being able to pose critical questions. From this research only little insight on how statistically literate citizens handle different ways of presenting data has been gained. Therefore it would be recommended that future research into this operational definition would consider involving graphs and/or diagrams.

No respondent is perfect and every statistically literate person shows their skills and attitudes in a different way. Looking back, the point could be made that the respondents were overqualified. Statistical literacy comprises of a minimal subset of skills needed, whereas the respondents showed a greater understanding than could be expected from the general population. Furthermore, although five knowledge bases and a cluster of beliefs, attitudes and a critical stance were proposed as jointly essential for statistical literacy, it does not necessarily follow that a person should fully possess all of them to be able to effectively cope with interpretive tasks in all reading and listening contexts. Finally, statistical literacy should be regarded as a set of capacities that can exist to different degrees within the same individual, depending on the contexts where it is invoked or applied. Someone could be statistically literate in certain contexts, or take a critical stance in their working environment, but never in their home environment. These three considerations do not affect the operational definition (The practical execution of statistical literacy). They do, however, influence the implications for education. Not everybody has to possess all shown skills and attitudes and some might be more suited for advanced classes.

To be able to correctly interpret the implications, two points need to be made about the respondents' working fields with regards to their vision on statistical literacy. First of all, the level of education differs between both practices. Where all teachers only see HAVO and VWO level students in their classes, clinical geneticists see a better reflection of the general population in their office, including (mostly older or immigrated) uneducated people. This means the teachers are not experts in what is realistic to teach on a lower level of education. The second issue concerns the attitude of people visiting the clinical geneticist. These people already made the decision to get information about testing. This means that they are already one step further, then the hypothetical situation (what would you do when your mother was diagnosed with cancer at age 56?) in which the respondents were placed. Although all clinical geneticists that were interviewed were aware of this difference, it might have influenced their view of the general population. Future research could take this into account by adding VMBO level teachers as a respondent group.

In this research a think aloud protocol was used to reach a better understanding of how respondents demonstrate their statistical literacy in practice. Two major concerns have previously been identified for the use of this method. Respondents describe being able to think faster than they can verbalize their thoughts. Furthermore, respondents could experience a cognitive overload, in that people have to be thinking whilst explaining their thoughts (Nielsen et al., 2002). This last problem has partially been avoided by using respondents who are experts in their domains and therefore will experience less cognitive load when thinking about the presented problem, as well as needing fewer words for their descriptions (Schmidt & Boshuizen, 1993a). Using fewer words to verbalize your thought process is a problem often encountered when interviewing experts, because it does not allow the researcher to capture what steps the expert is skipping in his/her description. The expert is also quite unaware of this, as he/she has incorporated different low-order concepts into a smaller number of high-order concepts, a process known as knowledge-encapsulation (Boshuizen & Schmidt, 1992; Schmidt & Boshuizen, 1993b; Van Someren et al., 1994). To combat this, respondents have been asked consistently to retrospectively describe their thought process, including the smaller steps encapsulated into high-order concepts. This problem likely occurred less frequently with the selected teacher respondents, for they are expected to explain concepts in small steps on a daily basis.

The framework for statistical literacy was created as a specification of literacy itself. However, it is impossible to determine whether characteristics of literacy are part of the operational definition of statistical literacy, without making a more abstract choice: Should the elements of general literacy be taken up into the elements of statistical literacy? This research has shown that different literacy skills are definitely required for statistical literate behavior, however going into this theoretical question goes beyond the scope of this article.

Finally, this research has used quantitative methods in a very limited way. It is possible to use a quantitative method to assess someone's statistical literacy, but this framework should be split into smaller parts first, after which the individual elements can be assessed. To accurately assess someone's understanding of, for example, a big idea such as variation in depth interviews or tests are needed. This way it is possible to put a person in the situation where the underlying basis of such a big idea comes to the surface. This allows one to assess whether someone really understands variation as a concept, or just remembers the definition. This makes data-triangulation a possibility, improving the validity of future research.

Implications

The operational definition of statistical literacy has many similarities with that of literacy itself. This makes it more difficult to describe where exactly statistical literacy ends, and where general literacy takes over. When looking at education, however, this implies that they cannot be dealt with separately. Teaching statistical literacy has to be educated in the broader light of literacy itself. The means critical questions need to be asked towards the statistics, but also towards the rest of the information. Furthermore, skills like talking to other people and asking for help when you need it must be touched upon; not being ashamed when you don't know something is a subject to address in education.

Mathematics classes should focus more on the implications of chances. There is too much focus on the skills of figuring probabilities, without knowing what it means. Respondents admit having difficulties themselves in imagining probabilities. This would not imply teaching statistics in a better way, but rather in a different way with another goal in mind. One teacher stresses this failure in teaching even more:

> *"I do not know how to imagine 87%. This is a lifetime risk, but what does that mean for the chances of developing it in the next year? That would help me in my decision… However almost no one is able to actually imagine the actual impact of a chance or risk of say 87% in your lifetime, which means that almost no one can actually make an informed decision the way we would like it to be made."* (B.G.)

Although this might be a bit too negative, respondents have the need to understand chances better, of developing a feeling with chances. One could even translate statistical literacy into the ultimate understanding of what a chance means as an accurate perception of risk, without the need for outside information:

> *"I would like for people to have more feeling with chances or other statistics they encounter. That might be a combination of all factors. Critical attitude, knowing statistics can help you, knowing the implications, but that you really know what 10 percent means. That you can feel it so to say."* (M.B.)

This can only be reached if attention is given towards not only handling statistical information, but also to the way that this affects students' perception of risk. Implications of risks in genetics specifically are also rarely talked about. Students learn how to calculate chances from a cross problem, but spent little to no time thinking about the implications of that chance. Although time and knowledge constraints are an issue, submerging students into one case and fully understanding the problems involves might teach them more then calculating multiple cross problems without understanding what that would imply. This idea supports previous research in contextualizing mathematical ideas done by (Pratt et al., 2011). When talking about statistics in new contexts - possibly in other classes than mathematics themselves - more attention should be given towards explicitly mentioning the statistics concepts involved and thoroughly describing thought processes behind seemingly simple calculations.

To take this one step further, for this case specific, there is also a lack of understanding what the basis of a probability is. To keep the same example in mind: where does the 87% come from, where do we base this on, and what are the underlying biological processes? If a better understanding of implications is needed, there is also a need to know where the probabilities come from going into the hypothetical situations. These implications join previous research (e.g. Levinson, Kent, Pratt, Kapadia, & Yogui, 2011) in their plea for a more multi-disciplinary approach in teaching SSI decision making to students. Students need to be made aware of these contexts for applicability of their mathematical skills, so they can be transferred to different context.

When different types of contexts are taught, time should be allocated towards the dispositional elements. As shown in the operational definition, in real life emotions and personal sentiments play a major role in defining the implications of a chance. This implies that students need to be shown how these emotions can affect decisions, how personal sentiments can affect decisions and how they might change over the course of someone's life. Not with the goal of making a perfect decision once you come across a similar problem, but to gain awareness for the effects and an understanding for the differences between people and how emotions change people's perspective.

Questioning the methodology might be too difficult to teach to students of all levels and even asking critical questions themselves are already a steep goal. Also understanding emotions is something that develops when you reach adulthood and it is unrealistic to expect the same kind of meta-vision about other people's emotions as one would from adults. These concerns illustrate that caution has to be taken in the level of statistical literacy we want to impose on our students.

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Appendix I – Adapted article to be used as the concrete case

My Medical Choice by Angelina Jolie

MY MOTHER fought cancer for almost a decade and died at 56. We often speak of “Mommy’s mommy,” and I find myself trying to explain the illness that took her away from us. They have asked if the same could happen to me. I have always told them not to worry, but the truth is I carry a “faulty” gene, BRCA1, which sharply increases my risk of developing breast cancer and ovarian cancer.

My doctors estimated that I had an 87 percent risk of breast cancer and a 50 percent risk of ovarian cancer, although the risk is different in the case of each woman. Only a fraction of breast cancers result from an inherited gene mutation. Those with a defect in BRCA1 have a 65 percent risk of getting it, on average.

Once I knew that this was my reality, I decided to be proactive and to minimize the risk as much I could. I made a decision to have a preventive double mastectomy. I started with the breasts, as my risk of breast cancer is higher than my risk of ovarian cancer, and the surgery is more complex. On April 27, I finished the three months of medical procedures that the mastectomies involved. During that time I have been able to keep this private and to carry on with my work.

But I am writing about it now because I hope that other women can benefit from my experience. Cancer is still a word that strikes fear into people’s hearts, producing a deep sense of powerlessness. But today it is possible to find out through a blood test whether you are highly susceptible to breast and ovarian cancer, and then take action.

Nine weeks later, the final surgery is completed with the reconstruction of the breasts with an implant. There have been many advances in this procedure in the last few years, and the results can be beautiful.

I wanted to write this to tell other women that the decision to have a mastectomy was not easy. But it is one I am very happy that I made. My chances of developing breast cancer have dropped from 87 percent to under 5 percent. I can tell my children that they don’t need to fear they will lose me to breast cancer.

It is reassuring that they see nothing that makes them uncomfortable. They can see my small scars and that's it. Everything else is just Mommy, the same as she always was. And they know that I love them and will do anything to be with them as long as I can. On a personal note, I do not feel any less of a woman. I feel empowered that I made a strong choice that in no way diminishes my femininity.

For any woman reading this, I hope it helps you to know you have options. I want to encourage every woman, especially if you have a family history of breast or ovarian cancer, to seek out the information and medical experts who can help you through this aspect of your life, and to make your own informed choices. I acknowledge that there are many wonderful holistic doctors working on alternatives to surgery.

Breast cancer alone kills some 458,000 people each year, according to the World Health Organization, mainly in low- and middle-income countries. It has got to be a priority to ensure that more women can access gene testing and lifesaving preventive treatment, whatever their means and background, wherever they live. The cost of testing for BRCA1 and BRCA2, at more than $3,000 in the United States, remains an obstacle for many women.

Life comes with many challenges. The ones that should not scare us are the ones we can take on and take control of.

Appendix II – Triggers for the mental model

My Medical Choice by Angelina Jolie

MY MOTHER fought cancer for almost a decade and died at 56. We often speak of "Mommy's mommy," and I find myself trying to explain the illness that took her away from us. They have asked if the same could happen to me. I have always told them not to worry, but the truth is I carry a "faulty" gene, BRCA1, which sharply increases my risk of developing breast cancer and ovarian cancer.

> This section should trigger respondents to talk about the heredity of the gene and possibly the risks of passing it on to the children.

My doctors estimated that I had an 87 percent risk of breast cancer and a 50 percent risk of ovarian cancer, although the risk is different in the case of each woman. Only a fraction of breast cancers result from an inherited gene mutation. Those with a defect in BRCA1 have a 65 percent risk of getting it, on average.

> 87% risk of breast cancer should trigger that it is a very high risk, which must be a lifetime risk.
>
> 87% risk is a very specific number, this should prompt critical questions.
>
> Only a fraction of breast cancers result from an inherited gene mutation, should prompt questions about the base risk of cancer.
>
> Only a fraction of breast cancer result from an inherited gene mutation, can be used later when talking about genetic testing.

Once I knew that this was my reality, I decided to be proactive and to minimize the risk as much I could. I made a decision to have a preventive double mastectomy. I started with the breasts, as my risk of breast cancer is higher than my risk of ovarian cancer, and the surgery is more complex. On April 27, I finished the three months of medical procedures that the mastectomies involved. During that time I have been able to keep this private and to carry on with my work.

But I am writing about it now because I hope that other women can benefit from my experience. Cancer is still a word that strikes fear into people's hearts, producing a deep sense of powerlessness. But today it is possible to find out through a blood test whether you are highly susceptible to breast and ovarian cancer, and then take action.

Nine weeks later, the final surgery is completed with the reconstruction of the breasts with an implant. There have been many advances in this procedure in the last few years, and the results can be beautiful.

I wanted to write this to tell other women that the decision to have a mastectomy was not easy. But it is one I am very happy that I made. My chances of developing breast cancer have dropped from 87 percent to under 5 percent. I can tell my children that they don't need to fear they will lose me to breast cancer.

> Going from 87% to fewer than 5%, should prompt questions regarding that 5%: is this big, is this small, how does it relate to the base risk?
>
> I can tell my children they don't need to fear they will lose met to breast cancer, could lead to questions regarding the heredity of the gene: the children could still be at risk.

It is reassuring that they see nothing that makes them uncomfortable. They can see my small scars and that's it. Everything else is just Mommy, the same as she always was. And they know that I love them and will do anything to be with them as long as I can. On a personal note, I do not feel any less of a woman. I feel empowered that I made a strong choice that in no way diminishes my femininity.

For any woman reading this, I hope it helps you to know you have options. I want to encourage every woman, especially if you have a family history of breast or ovarian cancer, to seek out the information and medical experts who can help you through this aspect of your life, and to make your own informed choices. I acknowledge that there are many wonderful holistic doctors working on alternatives to surgery.

Breast cancer alone kills some 458,000 people each year, according to the World Health Organization, mainly in low- and middle-income countries. It has got to be a priority to ensure that more women can access gene testing and lifesaving preventive treatment, whatever their means and background, wherever they live. The cost of testing for BRCA1 and BRCA2, at more than $3,000 in the United States, remains an obstacle for many women.

> It has a priority to ensure that woman can access gene testing, should prompt critical questions regarding the testing. This should be combined with the fraction that was mentioned earlier.

Life comes with many challenges. The ones that should not scare us are the ones we can take on and take control of.

Appendix III – Vignettes of all respondents

B.E. is a 39 year old male with 11 years of teaching experience in Biology. He teaches mostly VWO (has experience with HAVO as well) level students in the final years of their high school education.

TAP/Risk-analysis

This 87% is a high percentage on the basis of just one gene, which must have been inherited, and must be an average itself, or did they research all of her genes? 87% to 5% is also a lot, how did they get these numbers? The actual meaning of the numbers must be looked upon as well: Is 87% cumulative over 5 years, 50 years? If this is high or low depends on the base risk. When you get older, the chances will increase, but still, 5% risk after the operation still seems like a whole lot.

Angelina Jolie quite clearly arguments her personal choice, which will have a big impact. When you thoroughly analyze this article you come to the conclusion you need much more information for your own decision, although it is good she tells people to consult with medical experts. There are multiple other ways of looking towards this problem than just surgery.

If you have already witnessed the effects of cancer on your mother, your decision will be impacted. The other way around your decision will also affect your environment, so they should also be taken into account. You have to talk to someone else about this situation before taking a decision.

Vision

You cannot expect everyone to know about variation, but you can expect them to know about randomness. People should be able to link context of chances to different situations to understand the implications. They should also look where this chance came from, is this percentage applicable to your situation? On top of that your feeling with these chances is difficult. Estimating the probabilities of getting diseases is something that goes wrong a lot. Figuring probabilities is very difficult for students. We see this in figuring the probabilities of getting certain gene combinations

You don't need much contextual knowledge, as long as you search for it when you need it. You should be able to define the value, trustworthiness and reliability of the multiple sources you consult. This requires a critical attitude and questions, which are easier to pose if you already have basic knowledge. Reading of the source also requires you to understand the language used and different diagrams. Because you adopt a critical stance towards everything, your opinion about a source should not matter. Angelina Jolie is just a woman that has a chance on developing breast cancer.

Statistics can help you in your decision is the basis, because you have to ask other people for help when you cannot make a decision based on pros and cons yourself, or cannot read or judge sources adequately. You also have to consult other people to gather personal experiences, for talking about your choice in general, and to question yourself. Ask for someone to reason with you and check your interpretations, because you are not infallible and you are influenced by personal experiences.

Remarks

- “estimating the probabilities of diseases is something that goes wrong a lot” according to B.E., however after stating “5% risk after the operation still seems like a whole lot.” He seems to have that same problem.
- B.E. states that he finds it important that you search for the information when you need it, which is something that he himself also uses: “ you need much more information for your own decision”
- “They should also look where this chance came from, is this percentage applicable to your situation?” This means he wants people to dive into the methodology of the situation.
- Talking to others because you should doubt yourself, due to not being infallible and being influence by personal experiences is something that is added to the framework.

B.G. is a 64 year old male with 30 years of teaching experience in Biology. He teaches mostly VWO (has experience with HAVO as well) level students in the final years of their high school education. He is the only teacher with a PhD.

TAP/Risk-analysis

Only a fraction of breast cancers are caused by BRCA-1, or Breast Cancer Gene 1, which could be prevalent in different fractions in different populations around the world. A 65% chance in life to get breast cancer is a gradually increasing chance over a lifetime. Although I do not know how to imagine 87%. This is a lifetime risk, but what does that mean for the chances of developing it in the next year? That would help me in my decision. It does feel like such an unattractive risk, that I would want to know if I had the gene, if I was younger.

5% is kind of the percentage for people that do not have a genetic predisposition. And although there will be a chance the operation goes wrong, it will be smaller than the risk of developing breast cancer. Because of this risk, I would prefer other methods like a medicine to block the gene, if that was available. Let doctors tell you the consequences and risks of treatment and non-treatment. People can also be so afraid of the risk and consequences that they burry their heads in the sand and don't go out for help. I do not read this article in a scientific way, to look for misleading information. I read this story from the viewpoint of a woman in such a situation.

Vision

People should first weigh cold data to come to a conclusion and then discuss this with their surroundings in order to weigh in emotional arguments. No knowledge of genetics is necessary to make an informed decision. However almost no one is able to actually imagine the actual impact of a chance or risk of say 87% in your lifetime, which means that almost no one can actually make an informed decision the way we would like it to be made.

This also means education does not reach to goal of letting students understand the impact or meaning of a certain chance, only the way to calculate it. This goal is not reached in mathematics education, but also not in my own lessons, where there are some possibilities to do this. Although reaching total understanding of the impact of emotions on a chance/risk is impossible, already having an idea of the impact of emotions on risk-perception is a good start. Talk to people who can translate the risks involved into something you can comprehend. Talk to your surroundings and take a decision where you and others around you feel good about. This can be the wrong decision, but then at least you stand behind it.

The first four knowledge aspects are completely intertwined you need them all for a good understanding. Critical reasoning can only be reached when you understand all aspects of statistics. This is the most important attitude someone should have. However it is not possible to reach an understanding of all aspects of statistics in high school education, so teaching critical reasoning is kind of impossible. Learning how to use statistics? Maybe a better way to describe it is to be able to understand statistics, using is for researchers.

Remarks

- When asked about it, B.G. says he thinks there will be no deliberate mistakes in this piece. He reads this with the author and goal in mind, which means a woman in this kind of situation wanting to know what to expect. This means he can critically think, but chooses not to in this situation, because he does not take medical advice from Angelina Jolie.

B.M. is a 29 year old woman with 6 years of teaching experience in Biology. She teaches only VWO level students in all layers of high school education.

Tap/Risk analysis

The risk is different for every woman, then 87% is very specific. How can you determine the actual risk going down from 87% to 5%? The kids can still lose her to breast cancer with 5%, which is 1 in 20. Having kids, their age and her relation are not important in this issue. For risks of testing not only my mother is of importance, but also other female family members might have it. If we can monitor the development and intervene in time, I would not opt to do the surgery as fast. You need to consider the implications of knowing: these are not always positive.

Angelina Jolie should not end with a call for testing, which is irrelevant and misleading without the proper background information. Angelina Jolie also does not mention possible misdiagnoses, unrest or medical treatment, and is only one side of the story, which should never be viewed as the absolute truth. I feel like I need sources to check the information given.

Vision

A critical attitude combined with the ability and willingness to ask critical questions are the most important aspect of what we teach children. For reading a newspaper you also need to understand the language used. These skills are most important because they are connected to current events. You don't need to calculating chances and know statistical concepts to use them and so they are not needed for biology education. It would be very important to address the implication and origins of all kinds of numerical outcomes in biology, however we don't do this. From the mentality perspective also the critical attitude is most important, although all mentioned subjects play a role.

People should not take a decision based on anxiety, because that is a feeling and not knowledge. The most important thing for students is to develop an investigative attitude, know where to find information and then be able to determine what the source is and if it is reliable. Even if the source is a doctor, critical questions need to be asked. This attitude should be reachable for vmbo-T students, however a certain amount of maturity is also needed for these kinds of decisions, so also a VWO graduate of 18 years old will not be able to make a good decision. Specifically the Meta-vision of why you would not test is lacking. If you cannot find this information or criticise it, find people in your surroundings that are able to do this, or trust in your general practitioner. Develop a social security network, so you can talk to people about your decision.

Remarks

- "Having kids, their age and her relation are not important in this issue." Does not comply with "For risks of testing not only my mother is of importance, but also other female family members." Her kids also having a risk on the gene if she has it is of importance here.

- B.M. poses a lot of critical questions on the information given in the article. She does not only doubt the article, but also her own knowledge and wants to have more information before making a decision.

C.J. is a 55 year old woman with 15 years of experience as a genetic consultant. She performs patient consultations on a daily basis. She took part in a schooling program for nurses to become a genetic consultant.

TAP/Risk-analysis

She has adoptive children, so not all children are at risk of having the gene. Only a fraction is hereditary, this is important to mention. This also has consequences on testing. It is not like everyone can do a blood test. This is not true and is a part of the article we are not happy with. Also 87 % suggests that we can predict this very accurately, we take a range. Under 5% we also use, this is smaller than someone else's risk Not everybody can handle the fact that a test proves your genetic predisposition well. You will have to deal with it. There are people who do not test, so they don't have to deal with a difficult decision. Advice we give women that are predisposed are very different from the ones we give women that aren't, because of the different chances involved. The risk increases over time, so every year you wait with removing the ovaries, it increases. Angelina Jolie has a specific goal with this article and therefore doesn't include all information, e.g. you do the test and not always will you get a definitive result, or that not everybody is happy with the results of the surgery.

Vision

Everybody should have some knowledge of genes and their heredity, including that people that carry the gene, might not get ill. Students should be taught that there are a lot of possibilities with DNA testing, but should also know about the impact testing will have. Show students how emotions play a big role. Learn why other people can react different to situations than they do. Respect other people's choices, not testing is also an option. The feeling about a chance depends on a person's history: e.g. when someone already lost two sisters to breast cancer.

Language, context and figuring probabilities are most important to me. I think we should explain the context and how we figure the probability. We need to explain, in multiple different terms, why we think a certain chance is high or low. Concepts from statistics will play a role in the story, however you shouldn't use those terms in a talk with the patient. I think the framework is very knowledge-based. You cannot put your emotions into knowledge. And overcoming emotions in your decision is not always possible. Weighing pros and cons is not the most important thing. The focus should be on what a woman wants, how much worth does she put in keeping her own body versus wanting the risks to go down.

Educated people place too much emphasis on small number changes, while no education leads to over worrying about relatively low chances, because they go by feeling. Posing critical questions is something only educated people will do, but they are not needed in general healthcare. It is also a negative term I think, an open attitude is more positive: you have to be able to receive information and ask questions about what you want to know. Go and look for information and medical experts. Do not live in fear, but search help. Attitude, also versus the source, plays a major role in processing new information. It is difficult to be sure the patient has fully understood everything and makes a well informed decision. You can primarily find out through the questions they ask.

Remarks

- A critical attitude is viewed as something negative by C.J. This also goes along with her opinion that people should just go to the hospital to get information and that you should have full trust in your doctors.
- "We need to explain, in multiple different terms, why we think a certain chance is high or low." This equals influencing peoples' decision from weighing the different pros and cons.
- "It is difficult to be sure the patient has fully understood everything and makes a well informed decision. You can primarily find out through the questions they ask." This implies people don't say it themselves that they have not understood the explanation.
- It is unclear why C.J. makes a distinction between "Weighing pros and cons" and "how much worth does she put in keeping her own body versus wanting the risks to go down"
- C.J. often brings in emotions and feelings of other people, because she wants to emphasize the gene problem being a family issue, in which people might want different things.

C.M. is a 32 year old woman with 8 years of experience (of which 5 years where in training) in the field of clinical genetics. She performs patient consultations on a daily basis.

TAP/Risk-analysis

She acts like everyone can just do a test, but there has to be an indication according to our guidelines. Just believing that it is normal for the breast surgery to come first is not good. There are arguments to be made for both points of view. Not for all people the operation will go as smoothly as is described here; the author has some kind of motive. The author of the article is also not discussing screening as a preventative option when you test positive for the gene: it might be her experience, but there are more sides to this story! There should be more nuances and other options. Because she is a role model, people might see this as the way this should be handled, which is untrue.

The over-time advantage of screening vs operation is very, very difficult. It is a lot of information coming at you at once: multiple risks and options. Comparing multiple risks and options is a difficult thing to do. 87% surprises me, we say 60-80%. This is a lifetime risk, so when a patient comes in that is already 60 years old, a part of the risk has already passed, so her risk is lower. This is even difficult for me to understand. Some patients say: "I look like my mother, so I have more genes in common with her, than with my father." However, a random 50% chance is actually 50% and is not changed by prior events. When you test for results for children, you immediately also have a result for the parents. Same goes for identical twins.

Vision

Terminology of the context and estimating the impact of certain chances are most important in the patient's situation. Being able to identify at least the possibility of something being hereditary, but also understanding that having breast cancer does not imply a hereditary mutation. That something is a possibility, does not mean it has a big chance of happening. Furthermore communicating about risks, which is done with language, is important. Methodology is more for scientists: we are the ones that have to explain this and not the patient, although the objectivity does need to be questioned in this example.

Go to a doctor if you have concerns. Although theoretically everything gets explained in a consultation, it's a lot of information about a complicated decision. On top of that people act like they understand, because they don't want to admit otherwise. Being able to ask your important questions, as well as daring to pose them. Giving yourself the time to think about it and not go with your first thought, being able to weigh in new information about the problem. Your perception of risk does not need to be a static thing, this can change over the course of time.

People focus totally on the chance of getting, instead of not getting. The argument of Health above everything is being used perhaps a bit too much. When taking drastic decisions, 60-80% feeling as 100% is a fatalistic feeling, which should be talked about with a psychologist. The mother dealing with and dying from breast cancer will color the decision. In general screening or monitoring seems not to be considered enough.

Remarks

C.M. starts with using critical questions and -attitude as if these are the most important questions people can ask and their ability to pose them, this is not how this part is intended.

C.T. is a 55 year old male with 26 years of experience in the field of clinical genetics. He performs patient consultations on a daily basis

TAP/Risk-analysis

She uses both 65% and 87%, I do not understand why she would use both. 87% and 50% suggest some kind of accuracy that we do not have. We use a range of 60-80% and 30-60%. A blood test will only find a mutation, this means only people who have a mutation can find out their risk of breast cancer. BRCA is a condition. If it comes to expression, then it is a disease: cancer. The risk of breast cancer is higher, but only on a younger age, that's why usually the breasts go first. When you are 60, you have lived 60 years without developing breast cancer and your risk is lowered to 20%.

Not only she, but also the children are at risk of the gene, this is not mentioned in the entire article. I think she should say that breast cancer is normally not hereditary, that 10% of all woman get breast cancer, only 5% of those is hereditary, this is a small minority. These chances work multiplicatively. People think this is difficult, but do not show this, because they would feel stupid. A mother with breast cancer at 56 does not make me think of something hereditary. Even if your mother has breast cancer, but does not have the gene, your chances of developing it as well go up.

Vision

Language, context and critical questions are most important. People need to know nothing when they walk in, but it would be difficult without knowledge of fractions, knowing how to multiply fractions with fractions and how to put them into percentages: Understand and use probability calculations. Mendellian genetics would be helpful for people to understand. You need to understand the different forms of communication about risks before you can pose the critical questions. Critical attitude is important, that you pose questions if you don't understand something.

It is good to be aware of your personal attitude versus risk, but it stays an emotion that cannot be blocked out. People should always look at this situation as rational as possible, If you are overwhelmed with emotions you cannot make an informed decision. Simulating this decision is difficult, because in reality a death or cancer diagnosis precedes the consultation. I do not think that teaching a risk analysis prevents people from involving their emotions, but it would be easier to be more rational. I assume that people who lack the necessary knowledge can make weighted decisions. People sometimes want their doctor to make their decision, but we don't do that, maybe steer if they are really indecisive.

Educated people usually also have already thought about the consequences for their children, what it would mean for them, and what would happen to the risks if all preventative measurements will be taken. If someone already knows everything we can dive deeper into the matter and focus more on other aspects (then their own situation). When someone understands the rational part of the problem, it is much easier to talk about the decisions itself, because we don't have to inform them. You can take in only so much information, so if you already know a lot, you have more room for taking in the whole story.

Remarks

- “I think she should say that breast cancer is normally not hereditary”. Angelina Jolie mentions that this is a fraction of all breast cancers.
- “Critical attitude is important, that you pose questions if you don’t understand something.” This is not meant by a critical attitude.

M.A. is a 60 year old male with 26 years of teaching experience in Math. He teaches both VWO and HAVO level students in the final years of their high school education.

TAP/Risk-analysis

If your mother has the gene, then the chances of you having the gene are quite large. Her own children might also have it. Going from 87% to 5% lets you feel good about that decision, but 5% is still a reasonable risk. 87% is that for life? If this is per year then you can be sure you will not be around after 10 years. If it is not, the percentage will grow over time, so I want to know what it would mean for someone 10 years older or younger. The chances of breast and ovarian cancer need to be looked at separately. When considering testing, you have to look at what it would cost all woman of 40 years and older, what would you save? How many woman are there, how many die of breast cancer with and without the gene?

In this article I'm missing the negative side, the feelings, the costs, the troubles she has been through. I would like to know more about alternatives for the operation. This article might not have the goal of informing, but more telling people what happened with her.

Vision

You need to know that genes cannot be changed and you need to know what a percentage is. Language and critical questions are the most important ones. You need to interpret the numbers, graphs, methods of representation, do they accurately represent what I want to know. Is the methodology truthful and leading up to the correct conclusion. Context will come only later, when you really dive into the situation. Figuring probabilities is not something you do when you come into contact with something. You do this more instinctual, with a feeling, this feeling is important because you don't want to spend your whole day calculating chances about everything happening around you.

Talk about these things with your surroundings, you are not alone. Find (expert) sources to give you information about what the disease means and how it will develop, what the consequences of your choice will be. Then figure out what are my pros and cons, what is important for me? Find people that have dealt with this situation. Everybody makes their own decision and they are all correct, but denying that this is happening to you would be a bad thing, mostly towards your surroundings. I would not want to know the risk on everything that could go wrong, but you need to define for yourself with how much risk do you want to live.

Remarks

- 5% is quite a lot below the base risk
- 87% is a lifetime risk, if it would be yearly, it would be 99,8% in 3 years. Later he does realize this is not a death certificate, but the chance of breast cancer.

M. B. is a 34 year old male with 8 years of teaching experience in math. He teaches both HAVO and VWO level students in the final years of their high school education.

TAP/Risk-analysis

87% is a large chance of developing breast cancer and a reduction to 5% is a big one, however as long as a woman is unaware of her actual risk, 3.000 dollar is a lot to pay to find out.

I would like to know the risks of operation, the risk of inheriting the gene from the mother, the base risk of breast cancer, the amount of persons that we might be able to save with early testing and the false positives and false negatives. This is all not added by the author. This is also just the viewpoint of one person and this should not be taken for truth without checking the facts. She calls for testing, but I would have wanted to know the amount of persons out of 458.000 we might have saved with early testing. Angelina Jolie writes that it doesn't cause a lot of scars, so my appearance will not change much.

The impact of the decision should not be forgotten, like the impact on your femininity or the impact of the operation. Being able to change the risk from 87% to 5% would be a good and decisive reason to do something about it, sounds like that is less than for the average woman, but I would rather not know, so as not to get into that position of dealing with worrying about a maybe still healthy body.

Vision

You don't need to know about genes, but you do need to know about cancer. I would like for people to have more feeling with chances or other statistics they encounter. That might be a combination of all factors. Critical attitude, knowing statistics can help you, knowing the implications, but that you really know what 10 percent means, that you can feel it so to say. A decision should then ultimately be made with your feelings about the situation: What do I want and what is good for me.

When looking at the article itself, It is important that everybody is able to get the facts out of a story and reflect: do I agree with the decision made because of those or is the story guiding me in a certain direction. The viewpoint of the author might not be the whole truth. This approach requires a certain amount of critical view. A critical attitude is both a skill about questioning a story, and also an attitude to search for other sources.

Within such an article language is most important, because everything starts here. You have to ask critical questions about the language that is used. Language is never rational, something comes across in a certain manner by the language you use. It also stresses certain matters. Language is also not the same as communicating about something. You can understand a graph or text, but not the actual communication, you need more for that.

Remarks

- M.B. pays most attention to biology related concepts while reading the article and mentions exactly where he lacks certain knowledge. He only sparingly asks critical questions about the text, but in his risk analysis, he can precisely name the missing pieces of information he needs.
- M.B. talks a lot about his practice, but does not involve implications of chances in any way. This contrast his emphasis on people developing more of a feeling with chance.
- Not having to know about genes, while knowing about cancer can be translated to: you don't have to figure the probabilities, as long as you understand the implications.
- Once Angelina Jolie writes about scarring M.B. believes her immediately, he makes a difference between her being an experience expert, but not a medical expert.

M.R. is a 33 year old woman with 7 years of teaching experience in Math. She teaches both VWO and HAVO level students, primarily in the first years of high school education.

TAP/Risk-analysis

A faulty gene leads to breast cancer, but there are other factors too, because this is only a fraction. Almost half a million deaths are not from the wrong gene, so you cannot prevent them all. You would need to know the chance of getting the gene, when your mother has it. This chance is lower than when your aunt has it. You know what it means for your mother to get breast cancer, so you don't want this situation for your kids. Your kids could also have the gene.

Angelina Jolie doesn't mention all information I need for this decision, she only tells you about her choice. She has a specific goal in mind and I don't know if she is the best person to give advice. I would have wanted to know the chance on cancer without the gene. 87% risk is different for every woman, this confuses me, because a risk is already general. It must mean she has genes in common with women, from who 87% developed breast cancer. The surgery also does not influence your chance on ovarian cancer.

I would want to know exactly what the chances are of it going wrong, because then I might be able to choose for monitoring. And I think they can determine these chances quite accurately. To keep walking around with a ticking time bomb, the chance would have to be smaller than 5%. The uncertainty of not knowing there might be something wrong with my body would be most important to me. 13% of not getting it is negligible; The chances are way higher of developing it.

Vision

The difference with chance and something actually happening is a very difficult concept to grasp. All elements of the framework are important and influence each other, although I don't think people should be able to do the math themselves. You should be able to read and use diagrams. I think the fact that statistics can help you in these problems is the most important mentality, because this is the basis. I would want people to be able to go out and look for information. To look at an article with a critical attitude and see if they are objective. Do not base your decision on one source and check the quality. VMBO-t students should be able to do this, though they usually tend not to.

Although I have never thought about your own risk taking behavior, this is interesting. You have to realize your own thought process, how you deal with uncertainties, I agree with this. It would be good to be able to talk to friends about your emotions.

Remarks

- The feeling with a chance is difficult: To keep walking around with a ticking time bomb, the chance would have to be smaller than 5%. This is actually lower than the baseline.

- She applies thinking about your own risk taking behavior (mother has it, you don't want your kids to go through that), without realizing this ("never thought about own risk taking behavior").

Appendix IV – Interview protocol

Part 2: Risk Analysis

Kunt u nu afleiden welke beslissing u zou nemen:

2.1 Wat zijn de belangrijkste argumenten voor en tegen een test voor het gen en wat zou u doen? (Via Tabel) Geef Uitleg bij uw argumenten (**hoe zwaar ze wegen op een schaal van 1-10, met 10 als zwaarst wegend. Probeer aan te geven waarom dit zo zwaar weegt** Argumenten hoeven niet alleen uit het artikel te komen, mag ook als je zelf nog argumenten hebt.

Voor	Schaal	Uitleg inschaling

Tegen	Schaal	Uitleg inschaling

Beslissing: Wat zou u dan beslissen, wat zou het belangrijkste argument zijn?

2.2 Wat zijn de belangrijkste argumenten voor en tegen een test voor het gen en wat zou u doen? (Via Tabel) Geef Uitleg bij uw argumenten (**hoe zwaar ze wegen op een schaal van 1-10, met 10 als zwaarst wegend. Probeer aan te geven waarom dit zo zwaar weegt** Argumenten hoeven niet alleen uit het artikel te komen, mag ook als je zelf nog argumenten hebt.

Voor	Schaal	Uitleg inschaling

Tegen	Schaal	Uitleg inschaling

Beslissing: Wat zou u dan beslissen, wat zou het belangrijkste argument zijn?

2.3 Zijn er nog begrippen die je wilt toevoegen/toevoegingen op je verklaringen

2.4 is er informatie die je bent tegengekomen, die je irrelevant voor je beslissing of misschien zelfs misleidend vind voor je beslissing?

2.5 is er nog informatie die eigenlijk toegevoegd had moeten worden aan het artikel? Waavan je denkt dat deze eigenlijk wel belangrijk is, maar er niet in staat?

Part 3: The interview Protocol

1.1 Wat aan deze casus en gemaakte risicoanalyse komt u tegen in uw beroepsuitoefening?
En als u dan naar de verschillende dingen die je dan in je lessen behandeld kijkt, waar worden de meeste fouten in gemaakt?

1.2 Welke concepten worden vaak verkeerd geïnterpreteerd door burgers?
1.3 Wat is dan de fout die vaak gemaakt wordt?
1.4 Beinvloed dit de beslissing?
1.5 Is dat belangrijk in deze casus?

Veel scholen hebben als hoofddoel om leerlingen niet alleen kennis te leren, maar ze eigenlijk als competente burgers neer te zetten in de maatschappij en dat betekent dat ze zelf een beslissing moeten maken over deze situatie. Wat voor kennis, vaardigheden en houding hebben ze nodig om hier een goed geïnformeerde beslissing over te kunnen maken als het hun zelf overkomt (Moeder heeft borstkanker, ga ik testen/operatie ondergaan). Wat moeten ze kunnen voor een risicoanalyse zoals u gemaakt heeft? We gaan de kopjes 1 voor 1 af.

3.6 Dus wat voor kennis hebben ze volgens jou minimaal nodig om deze beslissing te kunnen maken?

3.7 wat voor vaardigheden zouden ze dan moeten hebben om deze beslissing te kunnen maken?

3.8 en wat voor houding zouden ze dan moeten hebben als ze met dit probleem geconfronteerd worden?

Wat zou je graag willen dat de burger in de Nederlandse maatschappij zou moeten kunnen of doen, op het moment dat ze geconfronteerd worden met deze situatie, dat de moeder wordt gediagnostiseerd met borstkanker?

3.9 Wat voor kennis zouden ze moeten hebben?

3.10 Hoe zouden ze tot een beslissing moeten komen?

3.11 Is dit een reëel doel voor alle burgers? (leg uit voor wie wel, voor wie niet)

3.12 Wat zou je dan willen van degenen die dit niet kunnen, jouw ideaalbeeld, wat zou je van hen verwachten, dat ze wel doen?

3.13 Werkt u wel eens met procenten en kans, zoals dat in deze casus naar voren is gekomen en op welke manier gaat dat dan in zijn werk?

Part 4: Het Framework

Bij het maken van een dergelijke risicoanalyse om een beslissing te maken, spelen allerlei typen argumenten een rol. Daarbij gelden rationele en ook emotionele argumenten. Daarnaast is er kanswerking omdat niet alle problemen en uitkomsten met zekerheid bepaald kunnen worden.

Hiervoor is een framework gemaakt uit theoretisch perspectief; Wat je voor kennis, vaardigheden en houding je zou moeten hebben ten opzichte van statistiek om een risicoanalyse te kunnen maken over een problem met kanswerking.

Een aantal zaken heeft u al genoemd, een aantal nog niet, daarom wil ik het schema aan u voorleggen en u vragen:

4.1 zijn bepaalde zaken hierin het belangrijkst

4.2 zijn er zaken hierin onbelangrijk, en kunnen die weggelaten worden?

4.3 zijn er zaken die toegevoegd moeten worden?

4.4 zijn er zaken die aangepast moeten worden

Part 5: tot slot

5.1 Heeft u het besproken artikel wel eens eerder gezien? Zo ja, waar?

5.2 Heeft iemand in uw directe omgeving weleens een dergelijke beslissing moeten maken, zo ja, leg uit?

Kenniselementen	
Kernbegrippen	Grote begrippen uit de statistiek als Variantie of Willekeur (Randomness)
Kansen uitrekenen	Vanuit verschillende bronnen van informatie, kansen berekenen over de waarschijnlijkheid van gebeurtenissen. Hierbij hoort ook de notie van (kwaliteit van) bewijs en het niveau van vertrouwen (level of confidence) en onzekerheid
Taal	Het begrijpen van verschillende vormen van termen (laag risico of lager risico) en methoden (diagrammen, percentages, kansen) om te communiceren over risico's
Context	Het kunnen verbinden van kansen aan verschillende situaties om de impact of implicaties van een bepaalde kans te kunnen inschatten.
Kritische Vragen	Vragen die gesteld moeten worden bij het tegenkomen van statistische informatie: bijvoorbeeld het doel van de schrijver en zijn objectiviteit. Verder moet ook altijd de methodologie onder de loep worden genomen

Elementen m.b.t. mentaliteit	
Overtuigingen en Houding	ik kan (tot een bepaald niveau) statistiek leren gebruiken
	Kansrekening kan je helpen met jouw beslissingen
	De overtuiging dat instanties e.d. altijd accurate informatie geven, of juist niet.
Kritische houding	Automatisch een kritische houding aan durven nemen om de kritische vragen te stellen
Persoonlijke houding ten opzichte van onzekerheid en risico	De implicaties van een bepaalde beslissing kunnen een beslissing een bepaalde kant op laten slaan als iemand graag risico's neemt of risico-aversie heeft

Appendix V – Interview protocol adapted version for clinical geneticists

Part 2: Risk Analysis

2.1 Wat zijn voor uw patiënten de belangrijkste argumenten die voor en tegen het ondergaan van de test wegen? Hoe belangrijk zijn deze argumenten voor patiënten? Deze argumenten hoeven niet alleen uit het artikel te komen

Voor	Schaal	Hoe gebruikt de patiënt dit?

Tegen	Schaal	Hoe gebruikt de patiënt dit?

2.2 Wat zijn voor uw patiënten de belangrijkste argumenten die voor en tegen het ondergaan van de operatie wegen? Hoe belangrijk zijn deze argumenten voor patiënten? Deze argumenten hoeven niet alleen uit het artikel te komen

Voor	Schaal	Uitleg inschaling

Tegen	Schaal	Uitleg inschaling

2.3 Komen de patiënten binnen met twijfel, met een los standpunt of met een vast standpunt?

2.4 Veranderen mensen van keuze en zo ja, welk(e) argument(en) is(zijn) dan doorslaggevend?

Appendix VI - Training for the TAP

We zullen tijdens dit interview eerst werken met een think-aloud protocol, daarna met een interview. Tijdens het think-aloud protocol ligt de focus op wat er in uw hoofd omgaat. Dit betekent dat het belangrijk is dat ik de volgende dingen in ieder geval hoor:

1. Wat vindt u belangrijke/opmerkelijke feiten/argumenten/standpunten die u tegenkomt in het artikel.
2. Leg uit wat deze betekenen
3. Op welke manier het je mening of gedachten beïnvloedt.

Ik ga nu een voorbeeld geven van wat voor dingen ik allemaal zou willen horen, u kunt ondertussen meelezen in de tekst. Belangrijk is om te onthouden dat het niet gaat om een perfect redeneringspatroon, maar om UW redeneringspatroon. U kunt niet alleen anders denken, maar ook andere zaken belangrijk of onbelangrijk vinden.

Kwade kansen

De Groningers willen weten hoe erg de aardbevingen bij hen nog kunnen worden. De prognoses worden zwarter.

Het is nog niet voorbij, weten de Groningers. Op 13 februari werd alweer een aardbeving met een kracht van 3,0 à la Richter geregistreerd en weer in het deel van Groningen waar al zoveel bevingen plaatsvonden: een paar kilometer van het beruchte Huizinge. Daar deed zich in augustus 2012 een beving met magnitude 3,6 voor – de zwaarste tot nu toe.

Nu wacht men gelaten op de bevingen die de magnitude 4,0 te boven zullen gaan, bevingen die minister Kamp in zijn Loppersumse rede van 17 januari niet langer uitsloot. Er is een kans van 10 procent dat er onder de tientallen bevingen van 1,5 en hoger die zich de komende drie jaar voordoen één of meer bevingen zullen zijn van 4,1 of zwaarder, zei hij kalm. Hij zei er niet bij dat dit, gezien de mogelijke gevolgen, een *groot* risico was, zoals het Staatstoezicht op de Mijnen (SodM) later wél deed.

Korte Som

Probeer eerst eens deze som op te lossen:

24*36 =

Vertel dus hardop hoe je dit aanpakt, wat je doet om deze som op te lossen, welke stappen je neemt

Overlijdenskans bij keizersnee drie tot vijf keer hoger

Een keizersnee leidt tot meer complicaties voor moeder en kind dan een vaginale bevalling. Behalve bij ‘stuitenkinderen’. Vrouwen die via een keizersnee bevallen hebben een twee keer zo hoog risico op ernstige complicaties en een drie tot vijf maal hogere kans om te overlijden aan de ingreep dan vrouwen die vaginaal bevallen. Dat is in een onderzoek in Zuid-Amerika weer bevestigd.

Nieuw aan dat onderzoek (British Medical Journal, 17 november) is dat de keizersnee zelf, en niet de situatie waarin de operatie gedaan wordt, nadelig is voor de moeder én voor de baby.

In de Latijns-Amerikaanse studie analyseerden de onderzoekers gegevens van ruim 97.000 bevallingen tussen september 2004 en maart 2005 in acht landen waaronder Cuba, Brazilië en Mexico. Het percentage keizersneden ligt daar hoger dan in Nederland: ruim een derde van de kinderen werd per keizersnee geboren.

De onderzoekers maakten drie categorieën bevallingen: vaginaal, een keizersnee 'op afspraak' omdat daar een medische aanleiding voor was, of een 'secundaire' keizersnee'. Een secundaire keizersnee is nodig als tijdens de bevalling een indicatie ontstaat, zoals bijvoorbeeld stagnatie in de ontsluiting of een vermoeden dat de baby in nood komt.

Deze week verscheen nog een tweede studie, uit Denemarken, die laat zien dat een geplande keizersnee nadelig kan zijn voor de baby (British Medical Journal, online 12 december). In dat onderzoek hadden kinderen uit die groep een hogere kans op ademhalingsproblemen, ten opzichte van kinderen die een vaginale geboorte of een 'secundaire keizersnee' hebben meegemaakt. Dat gold vooral als de baby's enigszins vroeg kwamen: kinderen die 'vroeg op tijd' (bij 37 weken) geboren waren, hadden een viermaal hogere kans dan kinderen die rond de uitgerekende datum met een keizersnee geboren werden.

In de Verenigde Staten en Italië ziet nu een derde van alle baby's een operatiekamerlamp als eerste levenslicht. Ook in ons omringende landen als Duitsland en het Verenigd Koninkrijk ligt het percentage keizersneden boven de 20 procent.

Dit leidt tot heftige discussies over het optimale aantal keizersneden. Volgens de Wereld Gezondheidsorganisatie zou het percentage keizersneden tussen de 10 tot 15 procent moeten liggen. Maar met name de Verenigde Staten en Zuid-Amerika overschrijden deze 'norm', wellicht door angst voor claims, flink.

Na een stijging in het percentage keizersneden in Nederland van 2 procent in 1970, via 8 in 1993 naar ruim 13 procent in 2001, lijkt nu stabilisatie op te treden. Dr. Anneke Kwee, gynaecoloog in het UMC Utrecht, vindt het Nederlandse getal acceptabel. Maar zij vindt wel dat we kritisch moeten kijken naar de indicaties voor een keizersnede: "Een keizersnede is niet een gemakkelijke manier van bevallen, zoals sommige mensen denken. Het is een grote buikoperatie."

Kwee promoveerde in 2005 op onder meer de lange-termijn-gevolgen van keizersneden in Nederland. Ze somt op: "Na een keizersnee kunnen direct complicaties ontstaan zoals een infectie of een ernstige trombose. Maar waar vrouwen niet aan denken is dat bij een eventuele volgende zwangerschap zowel zij als hun tweede kindje een verhoogd risico op complicaties hebben – waarbij overlijden van moeder of kind natuurlijk de meest extreme en gelukkig ook zeldzaamste is."

Appendix VII – Instructions used to code the TAP and risk analysis

Coderingsinstructie Framework statistical literacy

De codering die je direct gaat toepassen is aan de hand van een model over statistische geletterdheid. Deze geletterdheid wordt voor een deel bepaald door kennis en vaardigheden. Voor een begrip van de verschillende kansen die je in het dagelijks leven tegenkomt, wordt verwacht dat je deze kennis en vaardigheden toepast.

De respondent (in dit geval een 34-jarige wiskunde docent met meer dan 5 jaar ervaring) is gevraagd om het krantenartikel “my medical choice” te lezen en hierbij te vertellen wat hij denkt. In zwart staat het artikel beschreven, in rood is vervolgens aangegeven wat de gedachten van de respondent zijn. Van te voren is de respondent gevraagd dit artikel te lezen met het idee zelf een vrouw van 37 te zijn, van wie de moeder is gediagnosticeerd met kanker, maar wel met de kennis en vaardigheden van hemzelf. Na het lezen van het artikel worden enkele vragen aan de respondent gesteld. Ook de antwoorden hiervan dienen gecodeerd te worden.

De bedoeling is dat aan elke zin (afgesloten met een punt) één of meerdere coderingen worden toegekend. Deze coderingen staan hieronder uitgewerkt. Van de coderingen zijn eerst de definities opgenomen, daarna volgt een instructie met voorbeelden en non-voorbeelden. Na deze uitleg per onderdeel , volgt een verduidelijking wat aan verschillende elementen nu precies opgevat wordt als [C], [F] en [L].

Kenniselementen		
Big Ideas	**I**	Using the important, often abstract, concepts essential when communicating about statistics (e.g. randomness, variance, independence, mean). The concept itself can be mentioned or a clear example/interpretation of the concept can be used. Voorbeeld: “het risico voor elke vrouw is verschillend” is een omschrijving van de aanwezig variantie. Concepten zoals risico, percentage en kans zijn algemene begrippen (worden heel vaak in het dagelijks leven gebruikt) en mogen niet gescoord worden.
Figuring probabilities	**F**	Integrating information, including non-probabilistic information, in order to reach an understanding of probabilistic statements and to generate estimates about the likelihood of events. This means a calculation has taken place (or is proposed), or chances have been compared. Dit betekent dat: óf de respondent heeft een berekening gemaakt/voorgesteld. Óf de respondent vergelijkt twee kansen met elkaar. Dit hoeft niet in getallen te zijn gedaan. Voorbeeld: “als je weet dat je moeder het (borstkanker) niet heeft gehad, dan is de kans dat jij dat hebt natuurlijk ook niet zo groot” Voorbeeld 2: “Is dat 5% per jaar, wat is dan de kans dat je in 10 jaar dat soort kanker krijgt?”
Language	**L**	Switching between different terms (e.g. the difference between “low risk” and “lower risk than”, or “low risk” and “1%”) and methods (e.g. diagrams and graphs into words) used to communicate about risks. In het artikel wordt gesproken over een “5% kans op borskanker”. De respondent spreekt daarna over “een kleine kans” dan is er precies een dergelijke vertaalslag gemaakt. Taal kan ook gebruikt worden om het belang of de hoogte van een bepaalde kans te benadrukken. Voorbeeld: “Wat een hoog percentage, 87%!.”
Context	**C**	The ability to interpret and link probabilistic information to different situations to reach an understanding about the impact or implications of certain

		probabilities. Alleen scoren als er begrip blijk van de impact/implicaties van het risico. Non-voorbeeld: “50% kans op ovarium kanker” Voorbeeld: “5% kans op borstkanker is nog steeds veel” Een kans of percentage hoeft niet per se genoemd te worden, dit kan op twee manieren gebeuren: - Kansen zijn inherent aan de context: erfelijkheid en genen hebben in hun concept al een kans liggen. Voorbeeld: “Die adoptief kinderen zullen dat gen misschien ook hebben, maar niet van haar” - Begrip van de implicaties van de kans (in dit geval het overwegen om te opereren) wordt getoond. Voorbeeld: "Je kan geen kinderen meer krijgen na een ovariectomy” (een ovariectomy is het verwijderen van de baarmoeder)
Critical questions	**Q**	Questions regarding the truthfulness and completeness of the information. There needs to be an awareness of the writer’s purpose, objectivity and reasoning. Also the methodology should be questioned, because the quality of a study’s results depends on it (this involves typical problems and biases). De auteur heeft een bepaald doel voor ogen en de respondent is zich hiervan bewust door te twijfelen aan de waarheid of compleetheid van de informatie. - Hierbij is het mogelijk dat de respondent een zaken noemt die hij graag had geweten en daarmee aangeeft dat de auteur onvolledig is geweest. Voorbeeld: “Hoeveel zou zo’n operatie kosten, dat had ik wel willen weten” - Ook kan het zijn dat hij vindt dat de auteur onvolledig is geweest: Voorbeeld: “Ze zeg dat ze gewoon kon doorgaan met haar werk, alsof het allemaal een fluitje van een cent was, maar dat is het natuurlijk niet geweest” - Of dat de respondent aangeeft wat het doel van de auteur is. Voorbeeld: “in het artikel suggereert het woordje “maar” dat je dit zou moeten weten als vrouw zijnde” Methodologie gaat over de manier van uitrekenen van kansen. De respondent kan zich hierbij afvragen hoe dit is gebeurd en of dit op een juiste wijze is gebeurd. Vragen vanuit het niet snappen van een deel van het verhaal zijn niet kritisch. Kritisch gaat altijd over het doel/objectiviteit/methodologie. Non-voorbeeld: “ovarium kanker, wat voor kanker dat dan is weet ik niet”
Nothing	**N**	Deze code geven aan: -ongerelateerde zinnen aan het verhaal -vragen om opheldering (bijvoorbeeld van een vraag van de interviewer)

		-herhalingen van tekst uit het artikel zonder eigen toevoeging -het herhalen van een eigen statement, zonder verdere toevoeging Verder graag ook alle zinnen die geen code hebben gekregen, en dus geen statistische achtergrond hebben coderen met een [N].

Extra voorbeeld ter onderscheid van [C][L][F]:

Mijn kansen om borstkanker te ontwikkelen zijn gedaald van 87 procent naar onder 5 procent Daar kun je heel blij mee zijn met die beslissing, van 87 naar 5 procent gaan. Nog steeds een behoorlijk groot percentage trouwens, 5% op het krijgen van kanker is toch wel een redelijk percentage, of dat vind ik.

Daar kun je heel blij mee zijn met die beslissing, van 87 naar 5 procent gaan. [C][L]

-Er zit hier een begrip in van de implicaties van het risico, dit blijkt uit het positief opvatten van een grote daling van het percentage. [C]
-Het belang van de implicaties wordt nog eens verder benadrukt door het stukje: “Daar kun je heel blij mee zijn” en wordt daarom gescoord met een [L]
-Non-voobeeld voor [F]: 87% naar 5% gaat wel over het vergelijken van kansen, maar in dit geval wordt alleen de tekst van het artikel herhaalt. Er is geen begrip uit af te leiden. In dit geval daarom geen score voor [F]

Nog steeds een behoorlijk groot percentage trouwens, 5% op het krijgen van kanker is toch wel een redelijk percentage, of dat vind ik. [C][L]

-Een begrip van de implicaties: “een redelijk percentage”. Hoewel 5% laag is, is het in combinatie met kanker hoog, daarvoor moet je begrijpen wat de implicaties zijn [C]
-In de tekst staat 5%, er vindt een vertaalslag plaats van 5% naar een redelijk percentage [L]
-behoorlijk groot percentage is een benadrukking van de implicaties en krijgt ook een [L], echter wordt er niet dubbel gescoord.
-Non-voorbeeld voor [F]: de 5% komt rechtstreeks uit de tekst. Er wordt geen berekening, schatting of vergelijking uitgevoerd door de respondent.