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Communicating Personalized Cancer Statistics: Challenges and Opportunities

After a cancer diagnosis, many patients want truthful and complete disclosure of cancer statistics, such as estimation of life-expectancy (Fletcher et al., 2017). Such statistical information might help increase patients' understanding of diagnosis and involvement in a shared decision making process with their doctor about treatment (Elwyn et al., 2017). Even though cancer statistics have been communicated through various sources (e.g., decision aids or cancer websites), they are currently limited for a number of reasons.

First of all, cancer statistics are typically generic and not personalized, mostly because they are based on statistics of groups of prior patients. This makes it hard for patients to apply the statistics to their own situation (van Stam & van der Poel, 2017). Secondly, cancer statistics are difficult to maintain and are not always based on the most recent evidence, especially in paper-based decision aids. In this case, such numbers potentially do more harm than good (Montori et al., 2012). Finally, statistics expressed as percentages or probabilities are difficult to understand for the general public, and are not always communicated in a patient-friendly way (Gigerenzer et al., 2007).

However, using both insights from risk communication and developments in data science and artificial intelligence, the goal of our project is to tackle these issues. More specifically, we analyze data of millions of Dutch cancer patients in order to determine various personalized statistical information for individual cancer patients. Based on these analyses, we develop a tool which automatically generates personalized multimodal reports of the statistical information, in a format that is both accessible and understandable for patients.

The data used for this project come from the Netherlands Cancer Registry (NCR), which tracks all new cancer diagnoses and contains information about diagnosis, (e.g., tumor characteristics), treatment and vital status of patients. Similar population datasets have also been used elsewhere for prognostic tools (Henton et al., 2017). The scope of the current project

was restricted to the most frequently diagnosed forms of cancer in The Netherlands: prostate, breast and colon cancer. Before building the tool, several focus groups with patients ($N = 19$) and meetings with health professionals have been conducted to gauge their wishes and information needs, and also to receive feedback on the first sketches of the tool. Based on this, it was decided to disclose three types of cancer statistics as a starting point: incidence, survival, and conditional survival rates.

The tool will be installed at the Dutch cancer website (www.kanker.nl), on which patients can already view general cancer statistics based on the NCR. Additionally, our tool provides patients the opportunity to enter both personal (e.g., age) and disease-related characteristics (e.g., tumor stage) for receiving statistics based on patients with similar traits. The personalized statistics will be automatically communicated on a short result page for which we make use of a data-to-text system and natural language generation techniques (Gatt & Krahmer, 2018). These statistics are explained in a multimodal way, using both non-technical language combined with several types of visualization (e.g., icon arrays, bar charts, or line graphs), in accordance with guidelines and best practices from the risk communication literature (Garcia-Retamero & Cokely, 2017). Additional focus group and usability testing studies with both patients (breast, prostate and colon cancer) and doctors are currently being conducted.

However, during the development of the tool, several challenges have been encountered. First, although we expect that personalized statistics will be perceived as more relevant, and hence better processed than generic information, we should not underestimate the role of affect in this process (Zikmund-Fisher et al., 2010). However, studies show that for those patients who really want honest prognostic information the levels of hope maintain, even when the news is bad (Smith et al., 2010). The second challenge deals with communicating uncertainty. The estimated numbers we provide are based on prior cancer patients with similar traits and, inevitably, yield some degree of uncertainty. Although risk communication experts

recommend disclosing uncertainty to patients (Politi et al., 2007), it is still unclear whether patients really benefit from this information (Engelhardt et al., 2017). A final challenge relates to the automatic explanations generated, and particularly how to tailor sentences and explanations on poor prognosis and treatments with seemingly similar responses but various side-effects.

To conclude, shared decision making in cancer care requires that patient and doctor are both well-informed about the clinical case and personal situation at hand. We believe that our personalized approach of sharing timely, reliable, and relevant cancer statistics can play an important role in this.

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