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Epilogue



The results as presented in this thesis contribute to the further implementation of prognostic counselling, shared decision making and value based healthcare in head and neck oncologic clinical practice. Still, there are some hurdles to overcome. In order to truly involve head and neck cancer patients in treatment decisions and to empower them in their own care-process, a paradigm shift seems necessary. This transition is not only ongoing in head and neck cancer care, but in general healthcare as well. In this final chapter, we will contemplate on the future perspectives of patient centered care in head and neck cancer care and general healthcare.

OUTLINE OF A FUTURE CASE: PATIENT WITH HNSCC IN 2040



Mrs. E., a 47 year old female with cT2N2M0 HPV related cancer of the left tonsil. She lives together with her husband and three children aged 8, 11 and 13 years. She works as a data scientist at a large consultancy agency. When she first experience symptoms (pain in her left throat and a lump in her neck), she searches on 'IBM Watson for patients' the chances of having a serious disease. She makes an appointment with her general practitioner (GP), and fills out some personalized questions on the health-app on her smartphone. Her GP is also worried, given the answers to the Computer Adaptive Testing (CAT) questionnaire and her findings at physical examination. She enters Mrs. E.'s data into a webportal, and a diagnostic protocol is set in motion.

Mrs. E. is referred to a dedicated head and neck cancer team, with surgeons, radiotherapists, oncologists, paramedics and data scientists all working closely together. During the first appointment speech recognition software is used to register all necessary medical and psychosocial details of the conversation between Mrs. E. and her doctor. The data are used in an algorithm that predicts the best diagnostic-, treatment- and communication strategy. Also, a personalized prehabilitation program enables her and her family to prepare for treatment by exercise, nutrition and psychological interventions.

After diagnostic imaging and some blood tests, Mrs. E. is diagnosed with regionally advanced HPV related oropharyngeal cancer. Mrs. E. has several appointments with the team members to discuss diagnosis, prognosis and treatment options. Her immune response and genetic profile as well as the molecular characteristics of the tumor and clinical characteristics of Mrs. E are entered into *OncologIQ*. This dynamic prognostic model is continuously updated with data from national cancer registries, *RONCDOC* and from *Healthcare*

Monitor (which is incorporated in the *National Head and Neck Audit*). Costs and benefits of different treatment options are also taken into account in this model. Together with her husband, physicians and a dedicated case manager she chooses the treatment (proton therapy) that best suits her genetic profile and the molecular aspects of the tumor, and adheres best to her preferences regarding survival, quality of life and morbidity of treatment.

The follow-up phase during and after treatment is guided via the e-Health module of *Healthcare Monitor* on her smartphone. Mrs. E. uses wearables for physical self-measurement on a daily basis. If any abnormalities are sensed by the system she also answers personalized questions on her well-being. Mrs. E. may also answer these personalized questions any time she feels insecure or in need of support. The data are sent to the multidisciplinary team. An algorithm – based on tens of thousands of HNSCC patients all over the world – calculates every single day if medical care is needed. If necessary, direct feedback is provided to Mrs. E. herself and the most appropriate healthcare provider for the specific condition on that particular day. If needed, a large network of patients is available for online peer support.

HOW DO WE BECOME FUTURE-PROOF?

The future case of a Mrs. E. describes many technical and data-driven innovations. Several techniques will continue to make their way into medicine in the coming years.

Machine learning

Machine learning (ML) describes a subset of artificial intelligence (AI) that enables computers to continuously learn from historical data and make predictions about data using the information learned. Predictions about unknown variables are made, based on past experiences using large sets of data. ML is highly accurate and precise beyond the abilities of standard statistical techniques or human judgement to make predictions about outcomes in medicine.¹ ML has the potential to enable physicians to make actionable decisions based on all digitized health information ‘big data’. Due to the vast amount of data, there is a lower risk of having outliers, but the risk of bias and confounding is still relevant.

ML is also known as ‘a black box’. The input data can be seen, and the final outcome as analyzed by the algorithm can be seen as well. Traditional statistics still provide measures of effect size of individual variables, such as odds ratios. ML does not generate this kind of measures due to complex non-linear calculations. Therefore, it may be impossible, or at least very difficult for physicians, to interpret how ML actually progresses towards an

outcome.² However, whilst an algorithm based on ML is easy to use for physicians, the 'black box' phenomenon might not be an enduring obstacle. Direct and visual attractive implementation of ML algorithms in the electronic health record (EHR) would be very helpful to ease the use. Currently most EHRs contain gigantic amounts of patient data, but the majority of these data is not structured and therefore not directly usable by ML algorithms. A different set up of EHRs is necessary, with special attention being given to privacy of patient information and an efficient information exchange.

It is necessary to think about the ethical and educational consequences of the implementation of ML algorithms in healthcare. When computers predominantly influence clinical decisions, who is responsible when a harmful decision is made? And will this change how medical students are trained, when an algorithm may offer a repertoire of academic expert opinions due to its exposure to rare pathologies? Would the position of the omniscient professor become a thing of the past? Other aspects such as communication training and courses on interpretation and analysis of data will become essential.

Evidence for value based healthcare

New technology, increased patient wishes and changing population demographics all lead to an increased drive to spend more resources on keeping people alive and in good health for as long as possible. To ensure affordability, our attention will be increasingly focused on the value of healthcare. Evidence-based medicine (EBM) forms the basis of value based healthcare (VBHC). It became the dominant medical paradigm after 1990. In EBM, clinical decision making is based on the best available research evidence, instead of physicians' expertise, with the randomized clinical trial (RCT) as gold standard.³ However, the highest quality evidence is most often based on standardized groups of male, Caucasian adults and doesn't take into account individual patient values. VBHC integrates patient preferences (values) and scientific research into clinical practice by achieving maximum benefit per cost. And by seeing patients as medical consumers who participate in their own decision making process (SDM), patient centered care is made possible. Nevertheless, to be able to achieve the best value for a population, we must ensure that all interferences also have strong evidence of cost-effectiveness. Have available resources been divided fairly and optimally between different conditions? In the debate in general healthcare regarding SDM it is often presumed that SDM is only relevant for well-educated middle class health literate patients and is only a luxury for high income countries.⁴ It is important to feed our different experiences with decision making in (generally low-educated and lower class) HNSCC patients into this debate.

From God to guide

The case of Mrs. E. shows that the role of doctors will change.⁵ From being a traditional doctor choosing what's best for patients, towards a supporting guide choosing wisely together with patients while interpreting ML algorithm outcomes and asking questions like "*what matters most to you?*". 'Choosing wisely' is key since not everything that is possible (treatment wise), should be done. On the one hand because 'doing good' and 'doing harm' is not a binary decision and individual patients could have their own perspectives on this matter. On the other hand because of the financial aspects of an expanding healthcare system. After all, ML algorithms might help to improve both quality and cost of care by identifying effective and economical treatments. However, ethical issues may arise when an algorithm predicts that a certain treatment would be beneficial for an individual patient, but undesirable from an economic point of view.

While the role of doctors will change in the near future, 'the patient centered approach' will remain. After all, people like to be treated as 'people' instead of 'numbers'. In the current yearning for data-driven technological innovations lurks the danger of losing the real patient-centered approach. Even if algorithms meticulously could predict all individual aspects of diagnosis, treatment and prognosis, a need for personal attention will persist. Not only by helping patients to understand terms like probability or uncertainty of ML predictions, but mostly by offering a listening ear and by ensuring patients that a professional is taking care of them. Also, some patients will need more guidance than others, especially in case of health illiterate or severely ill patients.

The wise patient

Finally, the role of patients will change too. Having access to the right information, at the right time, delivered in the right way, leads to an increase in patients' abilities to take a more active role in their decision making and healthcare in general. This patient empowerment is really achieved when patients realize they can improve their medical outcomes by taking responsibility for their own healthcare decisions in partnership with their healthcare providers. This responsibility goes beyond taking care of the body by lifestyle changes or by adhering to decisions. It also means to be a smart healthcare consumer with an eye for both the individual as well as the altruistic perspective.

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