

EDITORIAL



## Look at the compass needle and see your course – navigation as a cancer survivor

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The internet has changed the world both for the opposition in Myanmar, for the typical physician in bedside cancer care, in research labs, in the medical industry and for cancer patients. Concurrently with access to an endless accumulation of data, informing treatment algorithms and development of new treatment strategies, also citizens are using this information hop as their main resource. Cancer patients utilize the capacity of the internet to educate themselves, to support their choices and to inquire about their treatments. Some patients are well prepared for their health care consultations, whereas others are not; it all depends on education, comorbidity and cohabitation status – the three top phenotypic aspects of a cancer patient in terms of prognosis [1–3].

Health literacy is one of the most important driving forces of these differences. In short, the concept of health literacy considers that patients have different basis for interpreting symptoms, communicating and interacting with the health professionals. Differences in education and cultural background result in variations in understanding and acting on health information [4,5]. Despite this fact, health literacy is not systematically considered in all the information material, handouts and conversations between health professionals and cancer patients.

When patients have finished planned treatments and walk out of the hospital door, they are on their own. In principle, the patient should be informed about symptoms to observe and be aware of changes in order to enable subjective observations of signs of recurrence or metastasis leading to a contact with the department. Concurrently with assigning this task to the patient, the health system has installed and maintains large enterprises entitled ‘follow-up’, which we know is of limited effect. A recent Cochrane review showed, that across all cancer sites these programs rest on quite limited evidence, to be polite both for effects on detection of recurrences, survival and on quality of life [6].

The increasing cancer survivor population use social media, wearables [7] and other digital platforms and concurrently, new ways of communication between the health system and cancer survivors see the dawn of light. These digital sources and instruments may support the patient in

obtaining support, in solving problems and in interpreting changes of the somatic or psychological health or in the social situation.

In this issue of *Acta Oncologica*, the secondary effects of such an instrument are reported. The authors describe the intervention as follows: ‘Oncokompas is an eHealth self-management application that supports cancer survivors to monitor their HRQOL and cancer-generic and tumor-specific symptoms. The main goal is to obtain personalized feedback and information on their scores and a tailored overview of supportive care options’ [8].

How is this done, one may wonder? The Oncokompas is measuring the situation by the patient filling in relevant information related to various aspects of quality of life and subsequently trying to teach the patient how to interpret symptoms, if any is reported. Finally, the Oncokompas suggests actions that the patients can take to address the actual problem. The teaching is quite simple as green feedback means that no action is required, orange indicates that the risk for problems is elevated and red light, that serious elevated risk is actually present and the patient is asked to contact the general practitioner or the specialized cancer department.

One may discuss both the validity and content of the quality of life scales applied, the algorithms for learning and the suggested actions. However, Oncokompas illustrates a serious approach to the current situation for the cancer patient. A situation in which cancer patients may use the internet as a resource, which has educational potential and may serve as a platform for a large part of the follow-up after cancer in the future.

One should remember that the internet *also* contains misinformation and as such presents a time-consuming problem for health professionals since patients may interpret their options and chances for survival incorrectly based on information from various websites or media.

Various platforms are launched to handle post-treatment surveillance and is expected to partly move responsibility from the health system to patients and relatives. Follow-up will no longer be defined as a passive behavior-awaiting

scheduled appointment. Rather, patients will be involved from date of diagnosis as partners in the trajectory of treatment decisions and surveillance of symptoms. Concepts as shared decision-making and patient involvement call for careful attention to patient resources like health literacy or social network for equity in access and participation.

### Disclosure statement

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