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Title: Changing cancer representations toward comprehensive portraits to empower patients in their care journey

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Advances in the field of precision medicine are revolutionizing cancer treatment.¹ Agnostic treatment approaches that focus on disease biology are being increasingly tested² leading to clinical progress and drug approvals.^{3,4} In addition, consistent data is highlighting the impact of the host in tumor response and prognosis^{5,6}. Therefore, contemporary oncology care plans go way beyond the primary anatomic tumor location and encompass cancer in its entire individual complexity including both biological (intrinsic to the patient or to the disease and its microenvironment) and non-biological factors (socioeconomic, cultural, environmental, behavioral). Technological progress allows for faster integration and analysis of multimodal omics data, leading to accelerated biomarker discovery⁷⁻⁹. Consequently, our understanding of cancer complexity and heterogeneity is set to evolve at a rapid pace in the coming years.

In recognition of the heterogeneity of knowledge among oncologists and the gaps in delivering guideline-concordant treatments across hospitals within and between countries, efforts from medical societies, the pharmaceutical and technology industry were created to continuously educate physicians on precision medicine.¹⁰⁻¹³ In addition, initiatives exist to develop and deploy clinical decision support softwares to assist physicians in their decision making¹⁴⁻¹⁷. However, a similar focus on educating citizens and patients about the complexities of cancer is lacking and their perception of cancer has remained limited mainly to its anatomical location. This minimalist vision of cancer among patients may give rise to several issues (**Figure 1**).

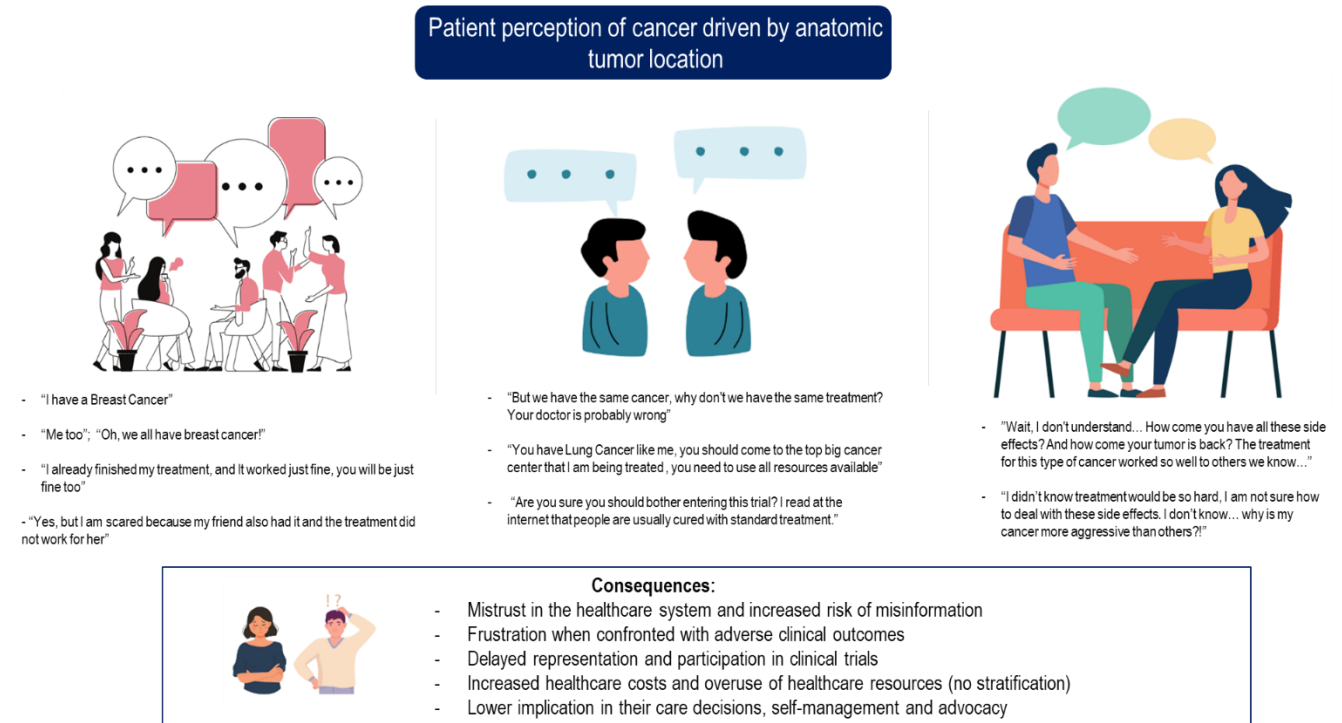


Figure 1- Patient perception of cancer driven by anatomic tumor location.

First, from a patient perspective, lack of patient understanding of disease complexity and heterogeneity and often simplistic view of their disease may create misleading expectations about treatment care plans and cause frustration when patients face adverse clinical outcomes or receive guideline-discordant treatment, fostering mistrust in the healthcare system and on healthcare professionals. Additionally, this lack of awareness increases the risk of misinformation and charlatanism. It may also create a barrier to patient's participation in their own care limiting shared decision-making, self-management and advanced care planning. Moreover, patient involvement in research and advocacy remains superficial preventing the co-development of patient-centered policies also hampering the timely inclusion and representation of patients in clinical trials. Finally, from a healthcare system perspective, it also results in an unsustainable and imbalanced use of healthcare resources as they are not stratified according to disease complexity.

Empowering patients towards participatory care through a comprehensive understanding of the individual cancer complexity that encompasses biology, integrated

with anatomical, medical, and social characteristics may lead to a paradigmatic shift on health care patient experience and engagement.

Patient empowerment is a growing concept that covers situations where citizens are encouraged to take an active role their own health participating, together with their healthcare professionals in medical decisions and in treatment care plans.¹⁸ At organizational level, it is assumed that patient empowerment is a fundamental piece for the transformation and evolution of the health-care domain and is serving as engine power for increasing the quality of health systems by policy makers¹⁹⁻²¹. In this sense, the European Commission²², and the World Health Organization (WHO)¹⁹ are actively supporting the development and implementation of patient empowerment tools either by supporting new models of chronic care or actions to promote health literacy skills.

Health literacy, defined as the ability to obtain, process and understand information and services to inform health-related decisions and actions^{23,24} plays a critical role in addressing these challenges. Low health literacy has been shown to negatively affect treatment outcomes and safety of care delivery²⁴, being associated with increased and longer hospitalizations, lower compliance with treatment plans and more advanced disease at diagnosis²⁵⁻³¹. It is also associated with increased and repetitive use of health services and prolonged health conditions³². Although limited health literacy affects all segments of the population³³, it is disproportionately higher in certain groups such as elderly, ethnic minorities, recent immigrants, and individuals from lower socioeconomic background³⁴.

The longstanding question remaining is how patient empowerment can be successfully achieved and used to promote a shift in the understanding of the disease and engagement with care pathway?

Healthcare professionals often report lack of time as a common barrier for shared decision making and participatory care.^{35,36} However, evidence suggests that empowering patients with education (e.g., list of pertinent questions to ask your doctor)

and shared decision-making tools beforehand does not necessarily significantly increase consultation length but rather improves its content and quality.³⁷⁻³⁹ Several empowerment strategies exist including the use of educational booklets,^{40,41} decision aids,^{42,43} educational seminars and nurse-led interventions,^{44,45} patient navigation,⁴⁶ peer support⁴⁷ as well as community resources.^{48,49}

More recently, digital technologies (electronic patient portals, mobile apps) have demonstrated to improve patient and provider communication^{50,51} and symptom management during active cancer treatment.^{52,53} They can also be leveraged to provide patient education, supportive care, and self-management support throughout the cancer care journey⁵⁴⁻⁵⁶ and also help patients engage with healthier lifestyles.^{57,58} These tools are therefore particularly well positioned to help patients understand individual cancer care complexity and participate in their care since diagnosis and navigate individual care plans. Also, they can decentralize, and simplify the access and implementation of the in-person empowerment strategies mentioned previously.

In addition, it is important to acknowledge that precision medicine is mainly driven by the collection and analysis of multimodal data, which are now increasingly embedded into electronic health records and subsequently accessible via end-user portals.²⁰ Making patients follow, share, understand and act on their health data, can be an effective approach for patient empowerment and it has been used in the management of chronic conditions⁵⁹ such as diabetes^{60,61} but not so much in cancer care so far.⁶² In fact, global policies now advocate that patients should have direct access to and control over their personal health data.^{63,64} As the use of patient portals and personal health data expands across institutions, proper patient education, empowerment and support will be needed to ensure the best use of this resource (such as enhancing data sharing among different stakeholders for research purposes and clinical care but also for the creation of personalized digital companions and virtual health coaches to assist patients using data from personal health records).⁶⁵

Ideally, such digital empowerment tool should equip both patients and providers to enhance communication and understanding of individual factors influencing treatment and response, leading to the creation and delivery of rationale, personalized and participatory care plans. It should also interact with other healthcare professionals involved in the patient care journey such as primary care providers, nurses, pharmacists, surgeons, radiologists, and supportive care specialists as well as caregivers to ensure a homogenous message, effective communication, and comprehensive care.

To be effective, these digital tools must be co-designed with a diverse group of patients, including those who typically face difficulties in care and are excluded from research. Moreover, to bridge the digital divide,^{66,67} they will need to be boosted with digital navigation strategies⁶⁸, local digital hubs,^{69,70} and literacy programs while also featuring adaptive user interfaces to cater to levels of digital literacy.^{66,71,72} In addition, data privacy,^{73,74} security⁷⁴ and interoperability standards^{75–80} will need to be rigorously followed to ensure that personal health records can be implemented in the clinic to empower patients. Also, the healthcare provider's autonomy and privacy should be considered in the setting of personal health records.

Lastly, and perhaps even more challenging than technical requirements, a cultural shift of the entire healthcare system from a paternalist and reactive care model to a proactive, preventive, personalized and participatory one is yet to be achieved⁸¹ and needs to be addressed through massive education policies for the current and next generation of healthcare professionals and citizens.²⁰ Importantly, the use of digital technology should not replace the role of the oncologist but optimize the patient-physician relationship and enhance the value of clinical encounters. In another scope, technology may also be used to automatize and decentralize administrative tasks related to patient care and research allowing more time for shared decision making during consultations.⁸²

As mentioned above, using digital tools to empower patients to embrace the complexity of their individual disease and participate more in their care, presents a unique set of challenges. Nevertheless, the potential benefits of this approach can be profound and far-reaching (**Figure 2**) Successful implementation of these tools will allow patients to have a minimum set of health literacy skills to decide if they want to become more engaged and participative in their care. This will likely increase the value of clinical encounters, facilitate shared decision making and self-management, reducing mistrust in healthcare and science. Furthermore, it could lead to a more rationale allocation of healthcare resources, reducing healthcare costs and care disparities and facilitating inclusion in clinical trials. Finally, patient empowerment accompanying the paradigm shift from anatomical site representation to molecular characterization, could accelerate advocacy, and contribute for better prevention and treatment policies for patients, caregivers and their families.

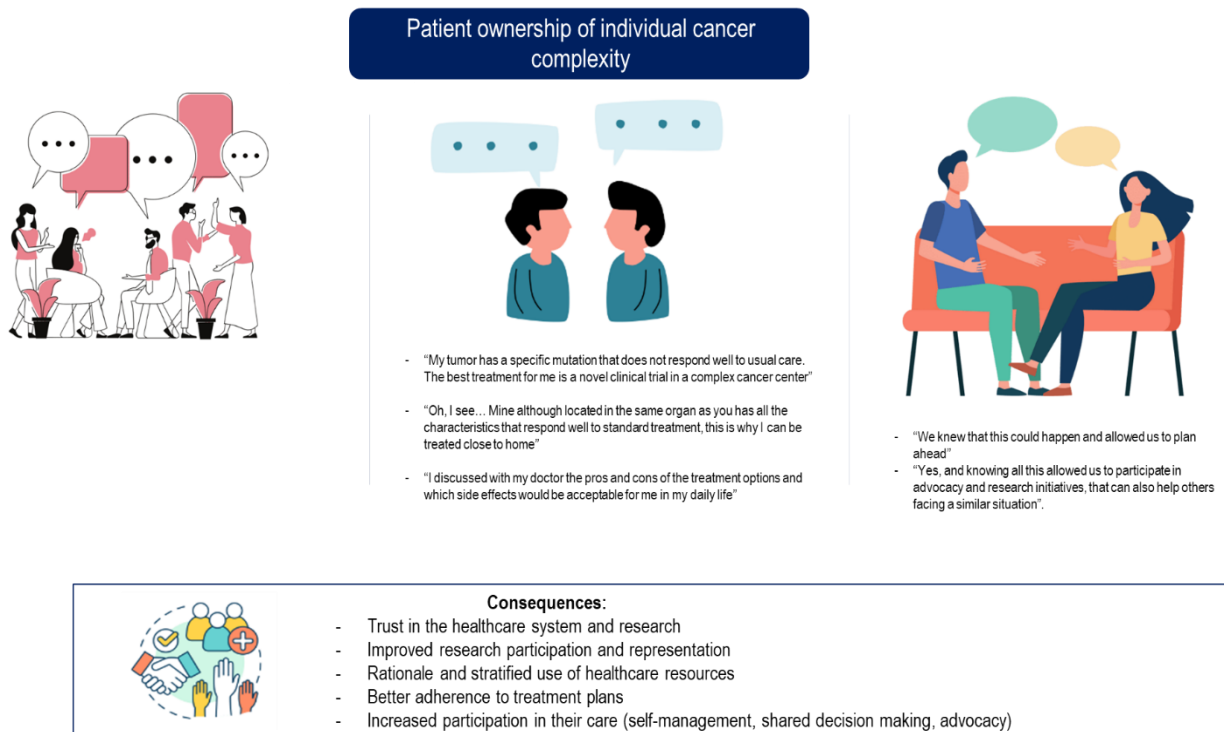


Figure 2- Patient ownership of individual cancer complexity.

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Figures titles and legends:

Figure 1- Patient perception of cancer driven by anatomic tumour location.

Figure 2- Patient ownership of individual cancer complexity.

Legends: *HER2*: human epidermal growth factor receptor 2; *PIK3CA*: Phosphatidylinositol-4,5-Bisphosphate 3-Kinase Catalytic Subunit Alpha.