Shared Decision Making in the Care of Patients With Cancer

Salma Shickh, PhD[1,2]; Konstantinos Leventakos, MD, PhD[3,4]; Mark A. Lewis, MD[5]; Yvonne Bombard, PhD[1,2,6]; and Victor M. Montori, MD, MSc[3]

overview

Shared decision making (SDM) is a method of care that is suitable for the care of patients with cancer. It involves a collaborative conversation seeking to respond sensibly to the problematic situation of the patient, cocreating a plan of care that makes sense intellectually, practically, and emotionally. Genetic testing to identify whether a patient has a hereditary cancer syndrome represents a prime example of the importance for SDM in oncology. SDM is important for genetic testing because not only results affect current cancer treatment, cancer surveillance, and care of relatives but also these tests generate both complex results and psychological concerns. SDM conversations should take place without interruptions, disruptions, or hurry and be supported, where available, by tools that assist in conveying the relevant evidence and in supporting plan development. Examples of these tools include treatment SDM encounter aids and the Genetics Adviser. Patients are expected to play a key role in making decisions and implementing plans of care, but several evolving challenges related to the unfettered access to information and expertise of varying trustworthiness and complexity in between interactions with clinicians can both support and complicate this role. SDM should result in a plan of care that is maximally responsive to the biology and biography of each patient, maximally supportive of each patient's goals and priorities, and minimally disruptive of their lives and loves.

SHARED DECISION MAKING IN THE CARE OF PATIENTS WITH CANCER

Shared Decision Making as a Method of Care

In recent years, the field of cancer treatment has seen a significant increase in the availability of treatment options, including immunotherapy, targeted therapies, and multidisciplinary care, which are being offered to almost every patient with cancer. Simultaneously, individuals living with cancer are exposed to a multitude of informational channels, including social media, which provide them with information about their disease and possible treatments.[1] The complexity of cancer care and the abundance of cancer-related information complicate the development of care plans that make sense for each person. Cocreation of such plans may lead to plans that maximally support patient priorities, respond well to the patient's situation, and minimally disrupt their lives and loves.[2] Doing so may also increase patient satisfaction with treatment, boost confidence in the plan of care, and improve trust in the medical team.[3]

Shared decision making (SDM) is a collaborative approach to care by which patients and their clinicians work in partnership to address the problematic situation of the patient and respond by cocreating sensible plans of care.[4,5] SDM begins with determining the nature of the patient's situation, which often involves insights that only the patient and their family can provide, including aspects of the patient's biology (the nature of the cancer itself and of the health state and comorbidities of the patient) and biography (the personal history of the patient, social and economic contexts including forms of discrimination, exclusion, and injustice; their relationships and responsibilities; and their expectations and dreams) and their mutual interactions.

In the case of cancer care, clinicians must work with patients, with competence and compassion, to develop a practical cancer care plan that is informed by relevant evidence, addresses emotional aspects of the problem, and is both feasible and sustainable for the patient.[6,7] Seen in this way, SDM is not an additional task for clinicians but a fundamental method of care that is central to the clinician's art, similar to history taking, physical examination, selection and interpretation of diagnostic tests, and patient education and counseling.[8]

How Can SDM Contribute to the Care of Patients With Cancer?

We have previously described how to implement SDM in practice[8]; these steps can easily be translated in everyday cancer care practice.

Foster a productive conversation. The initial step involves promoting productive dialogues that encourage

Author affiliations and support information (if applicable) appear at the end of this article.

Accepted on May 5, 2023 and published at ascopubs.org on June 20, 2023: DOI https://doi.org/10.1200/EDBK_389516

PRACTICAL APPLICATIONS

- Shared decision making (SDM) is a method of care on the basis of conversations conducted to arrive at a cocreated plan of care that addresses the problematic situation of each patient.
- Unhurried conversations, SDM tools, and collaborative deliberation methods are essential to coproduce care plans.
- Health care systems that favor the processing of people rather than the care of patients are hostile to methods of patient-centered care, such as SDM, and must be radically reformed.
- The experience of patients contributing to care that fits requires access to trustworthy information and expertise within and between clinical encounters.

active patient-clinician collaboration, facilitate the process of care plan development, and support the cocreation of a comprehensive care plan.[9] Throughout the patient's journey, from screening to cancer diagnosis, treatment, and end-of-life discussions, the clinician is tasked with exploring with curiosity the patient's problematic situation, identifying any changes in their health status, concerns, or shifts in their life circumstances. This crucial phase involves the clinician's ability to understand the patient's condition and assess the effectiveness, feasibility, and desirability of the current care plan. It is particularly critical in cancer care, where biologic parameters such as laboratory tests and imaging, alongside other factors such as treatment burden,[10,11] financial toxicity,[12,13] and insurance coverage,[14] contribute significantly to the patient's problematic situation.

The SDM team—patients and clinicians—engages in a continuous and collaborative process of noticing and responding, striving to arrive at an approach that makes sense intellectually (ie, reflects the situation as understood and the response is based on the best available evidence),[5,15] practically (ie, given our understanding of what capacity can be mobilized, what may prove to be feasible to implement in the life routines of the patient, and within what is available in the health care system), and emotionally (ie, addresses, responds, and supports the emotional experiences and feelings of those involved).

Through a thorough examination of the available actions (including those that the parties can identify, uncover, or invent) to address the situation, the team may need to reframe the issue and reformulate the problem at hand.[9] For instance, a patient facing a cancer diagnosis with poor prospects for a cure may initially seek aggressive treatment but may ultimately reframe the situation as one of the seeking ways to achieve a peaceful and dignified death. In such cases, alternative options must be identified, evaluated, and implemented as needed. Throughout this process, the patient plays a critical role in determining the extent to which the plan of care is likely to be effective, feasible, and compatible with other treatments and daily routines, that is, to what extent care fits at the point of life.

Purposefully select and adapt the SDM process. There are four distinct ways in which patients and clinicians can work together to address the patient's problematic situation: (1) focusing on matching preferences, (2) reconciling conflicts, (3) problem-solving, or (4) meaning making.[9] Each of these forms of SDM and representative applications in cancer care are given in Table 1.

In our experience, clinicians and patients who do SDM well work within a form of SDM until a better one becomes apparent and they flexibly, gracefully, and perhaps intuitively switch according to the challenges uncovered during the conversation.[16]

Protect the space (and quality time) for SDM. For SDM to be effectively conducted, it is essential for both patients and clinicians to engage in the process. The conversation itself serves as the primary workspace within which this collaborative work takes place. As such, it is crucial that the conversation space are deliberately designed to promote and facilitate the SDM process.[17] In today's world, this conversation space may take the form of remote consultations[18] and virtual platforms because of the widespread adoption of telehealth in oncology care.[19,20] To ensure a conducive environment, clinicians vigilantly eliminate any visual or auditory distractions that may impede the decision making process. This involves protecting the conversation space and the allocated time for these consultations. Policies must be implemented to safeguard the sacred time of consultation with patients and minimize electronic medical record burdens to eliminate any potential disruptions or interruptions. It is paramount that clinicians (and those whose job is to support care) take these measures to optimize the SDM process and ultimately improve patient outcomes.

Make the most of participation. Having set the stage for an unhurried conversation,[17] it is necessary to determine who should participate in that conversation, including patient caregivers and other significant people in the patient's life as well as clinicians from other specialties with a stake in the decision, a common situation given the high prevalence of multidisciplinary care. Multidisciplinary clinics and multidisciplinary cancer care patient navigators can help to avoid confusion and secure better coordination of care. These stakeholders can take part or assist the established patient–clinician dyad in cocreating a plan of care.

TABLE 1. Forms of SDM (adapted from the study by Montori et al[8])

SDM Form Method Description	Situations in Which This Form May Be Preferred
Matching preferences	
Patients and clinicians compare features (ie, efficacy, burdens, side effects) of the available options and match them with the patient's values, preferences, goals, and priorities. They may use an SDM tool to share information about the options. Patients and clinicians deliberate until the best match is identified	Patients and clinicians discuss options for adjuvant treatment in early-stage resected lung cancer
Reconciling conflicts	
Using a collaborative process, the clinician helps the patient articulate the reasons for their position while reconciling those reasons with the varying possibilities ahead	Patients and clinicians discuss options for clinical trial participation when the patient is afraid of being treated with placebo—while there is no placebo in this trial
Problem-solving	
Potential solutions are tested—in conversation or therapeutic trials—and become justified on the basis of the extent to which these can demonstrably and successfully address the problem and improve the patient's situation	Patients and clinicians discuss different ways in which the toxicity of a systemic therapy can be managed and mitigated given the comorbidities of the patient
Meaning making	
Using conversations, patients and clinicians develop insight into what the patient's situation means, at a deep level, to the patient and their community and to find the reasons within that process for pursuing a particular approach	Patients and clinicians seek to make sense of the lack of cancer response to therapy and develop a way to frame the situation and bring patient, family, and others into a joint understanding that the patient care has new goals and approaches

Abbreviation: SDM, shared decision making.

Deploy useful tools. To facilitate effective SDM, it is important for both clinicians and patients to carefully consider the tools that are introduced into the conversation. This includes specialized tools that have been specifically designed to support forms of SDM that have demonstrated effectiveness, usability, and desirability. Depending on the circumstances, various tools can be used to aid in the decision making process, such as self-management logs, patient-reported outcome trends, and results from ancillary laboratory and imaging tests, all of which can support the problem-solving mode of SDM. One notable tool is the My Healthcare, My Life conversation tool.[21,22] This tool is specifically designed to foster a mutual understanding between patients and clinicians regarding the social and economic challenges that patients may encounter on a regular basis and how these factors may affect their health and the implementation of treatments.

The Making of an SDM Tool

The team at the Knowledge and Evaluation Research (KER) Unit is one of the several groups worldwide which has been developing and evaluating SDM tools.[23] The KER Unit has been working on this for more than a decade, pioneering user-centered design and participatory action research in clinical practice.[24]

Our process follows the steps described in Figure 1:

1. Assemble a multidisciplinary team comprising designers, patients, oncologists and other clinicians, decision making scientists, and a stakeholder group comprising oncologists, primary care clinicians, patients, a designer, and other stakeholders.
2. Consult with a Patient Advisory Group—a group of 8-10 volunteer patients living with the condition of interest who engage with developers to ensure that the work is pertinent and responsive to patient priorities. This group helps identify relevant outcomes that must be considered in both the evidence synthesis and the SDM tool.
3. Synthesize the evidence about the benefits and potential harms and inconveniences of potential cancer treatments including existing practice guidelines. If pertinent, after reviewing the results with the stakeholder group, we produce an evidence table that outlines the efficacy, harms, and practical implications for each management option (ie, adjuvant treatment or surveillance).
4. Conduct observations of current treatment conversations between patients and their oncologists. Over 95% of clinicians and patients routinely consent for video recording. We use institutional review board–approved procedures for obtaining and securely storing the recordings and accessing them with rigorous protection of patient and clinician privacy.
5. Design a first prototype—using information from the evidence synthesis, insights about outcomes and practical considerations from our patient advisory group and on the basis of what is hard or difficult in existing, directly observed, conversations, an experienced interaction designer produces a first prototype of the SDM tool. This

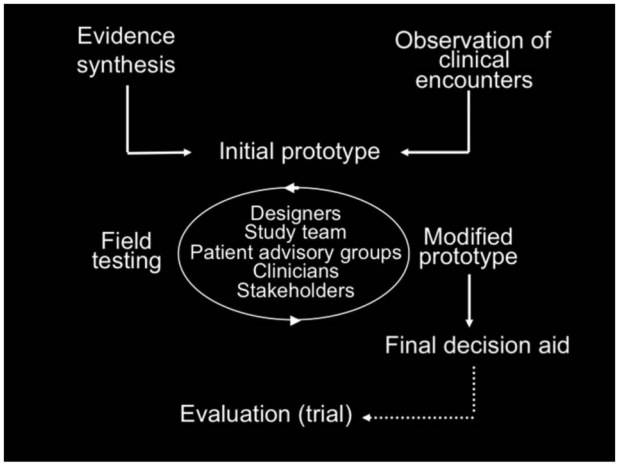

FIG 1. Design process for encounter decisions conducted by the Knowledge and Evaluation Research Unit at Mayo Clinic.

prototype pays attention to the needs in practice primarily, while seeking adherence to the International Patient Decision Aid Standards.[25]

6. Field testing: the prototype is used in consultations by oncologists and patients. Each clinician will use it in about three to four real-life clinical encounters either directly observed or video recorded. After each use of the prototype, we ask patients and clinicians about their experience and whether they recommend any changes. On the basis of observations and participant input, the developer team modifies the tool and field tests it again. Arriving at a final prototype that patients and clinicians find useful, usable, and desirable usually requires three to five iterations and about 20 or so encounters.

Two Examples of SDM Tools for Cancer Risk

The Thyroid Cancer Treatment Choice is a tool grounded in evidence that facilitates the discussion of treatment options for papillary microcarcinomas. Pilot testing has indicated that using this tool enhances the acceptance of active surveillance, suggesting that it is a viable and desirable alternative for patients who are well-informed. Following its initial implementation as a paper-based instrument, Thyroid Cancer Treatment Choice has been adapted as an electronic tool. This new version (Fig 2) permits risk stratification on the basis of age and cancer progression and can be integrated into electronic health records for individualized care. Furthermore, this updated version includes the option of ultrasound-guided percutaneous ethanol ablation for institutions that provide this form of treatment.[26]

Non–small-cell lung cancer (NSCLC) Adjuvant Choice is a tool for patients and clinicians to engage in SDM for the adjuvant treatment of resected NSCLC. Given the advances in the adjuvant treatment of NSCLC and the incorporation of immunotherapy and targeted treatments in selected patients, this tool supports the discussion for personalized options of the patients on the basis of their disease's biomarkers. The prototype was developed to include a personalized calculator of the patient's risk of dying within 5 years depicted in a 100-person pictograph on the basis of available treatments, stage, PD-L1 expression, and EGFR mutation status. It supports the discussion of the different options by depicting each treatment option's special considerations and side effects (Fig 3). The tool is undergoing field testing.

Making (CANCER) Care Fit Manifesto

In March 2021, a group of 25 individuals led by Dr Marleen Kunneman and hailing from seven countries convened to identify and deliberate on the indispensable prerequisites for establishing care that is tailored to the unique needs of each patient.[2] Their official statement states the necessity for clinicians, patient advocates, policymakers, researchers, and editors to collaborate toward promoting and facilitating initiatives that streamline the process of personalized care, in conjunction with patients and their caregivers.[27]

We contend that the principles described in the manifesto are very relevant to cancer care. In line with the Making Care Fit Manifesto, care optimized for patients with cancer must adhere to the following criteria:

1. Maximally responsive to patients' unique situation.
2. Maximally supportive of patient priorities.
3. Minimally disruptive of patient lives.
4. Minimally disruptive of patients' loved ones and social networks.

One could argue that an additional requisite is now essential—that care processes and systems be maximally disruptive of structural inequities.

A PATIENT REVOLUTION IN CANCER CARE?

Efforts to implement patient-centered care, such as SDM, however, face seemingly adverse conditions that drive toward efficiency, making it difficult to implement these practices routinely.[28]

For patient-centered care to thrive, health care organizations must foster conditions that favor care.[29] In addition to ensuring the provision of evidence-based treatments, clinicians and patients should be able to cocreate plans of care that maximally respond to the goals and priorities of each person and to their biologic and biographical situations and that are desirable, useful, and feasible in their lives. Every clinician and patient would want this, and health care organizations must ensure that they enable patient-centered care within relationships of trust not simply transactional encounters.[30] Achieving careful and kind care for all will facilitate formation, practice, and innovations in patient-centered care, including SDM as a method for cancer care.

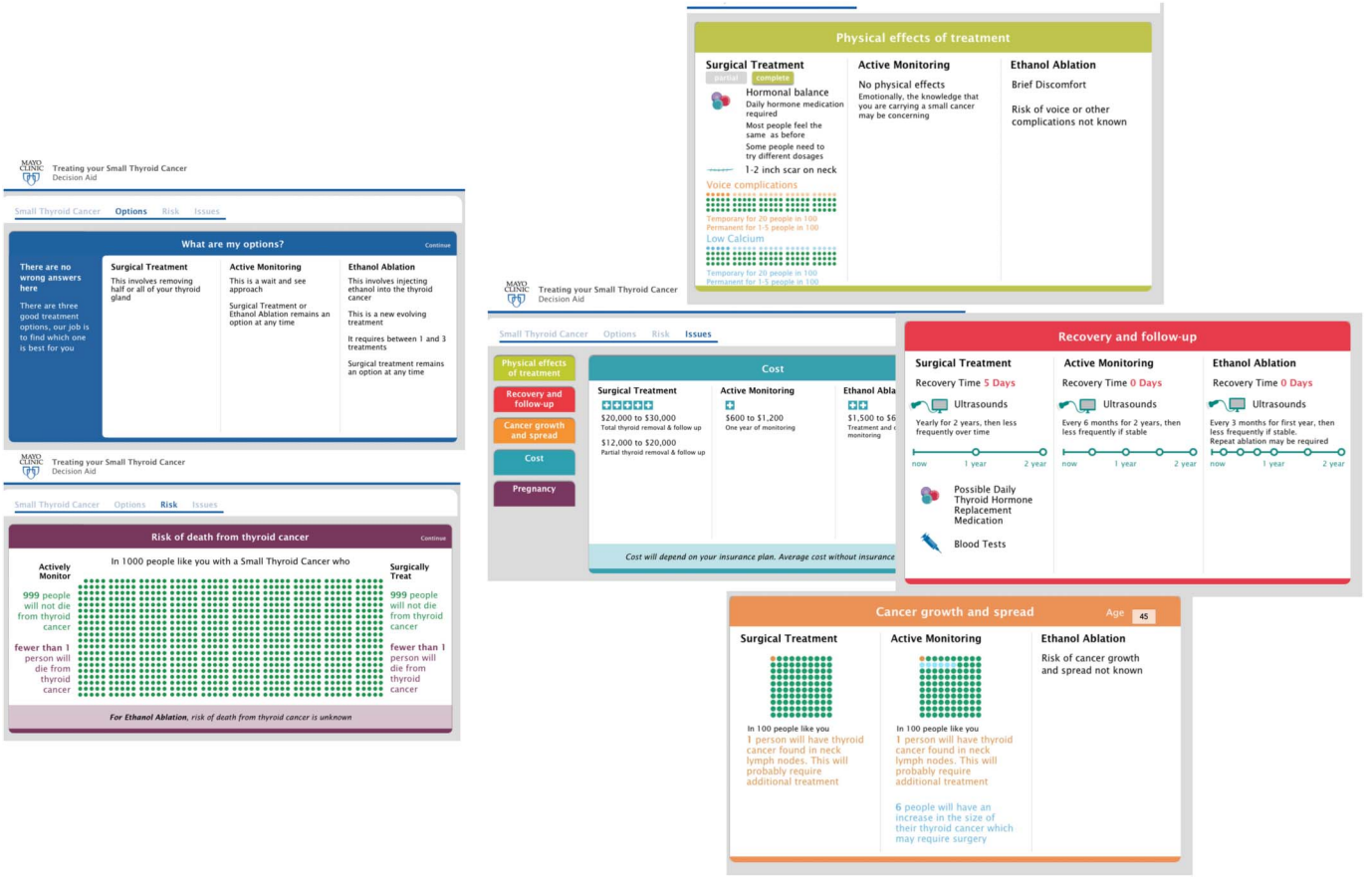

FIG 2. Screen captures of the online shared decision making tool about the treatment of patients with small thyroid cancer. Reproduced with permission. 2023 Mayo Foundation for Research and Education.

Yet, innovations to facilitate patient-centered care and SDM cannot wait for more supportive care conditions. Such innovations are in fact emerging in many cancer settings, especially within cancer genetics. Here, patients routinely undergo genetic testing, a test that can have a broad range of implications for the patient and their family, underscoring the need for SDM.

DIGITAL TOOLS TO ADVANCE SDM FOR CANCER GENETIC TESTING

Genetic testing to identify whether a patient has a hereditary cancer syndrome (HCS) represents a prime example of the importance for SDM in oncology. Nearly one in 10 patients diagnosed with cancer have an underlying HCS.[31-33] Patients with HCS have a germline gene mutation that predisposes them to develop multiple, early-onset cancers over their lifetime. Common types of HCS include hereditary breast and ovarian cancer (HBOC) syndrome because of *BRCA1/2* gene mutations and Lynch syndrome because of mutations in mismatch repair genes.[32,34,35] Females with HBOC have increased risks for multiple cancers, including 60%-80% chance of developing breast cancer and 11%-44% chance of developing ovarian cancer, whereas males have a 1%-8% risk for breast cancer and 20%-60% risk for prostate cancer.[31,34-40] Males and females with Lynch syndrome are at up to a 70% risk for colorectal cancer, 18% risk for stomach cancer, and 20% risk for small bowel, hepatobiliary tract, urinary tract, brain, and skin cancers (sebaceous neoplasms),[31,41-45] with males also having a 20% risk of prostate cancer[41-44] and females also at risk for endometrial cancer (12%-46%), breast cancer (13%), and ovarian cancer (20%).[41-44] Given these high risks, the National Comprehensive Cancer Network, ASCO, and the American Society of Breast Surgeons recommend that patients with a personal and family history of cancer undergo genetic testing to identify whether they have an underlying HCS and advocate for the importance of SDM in counseling patients for genetic testing.[46-49]

SDM is important for genetic testing because results have broad implications, including influencing current cancer treatment, changing future cancer surveillance, triggering management changes for relatives, generating complex

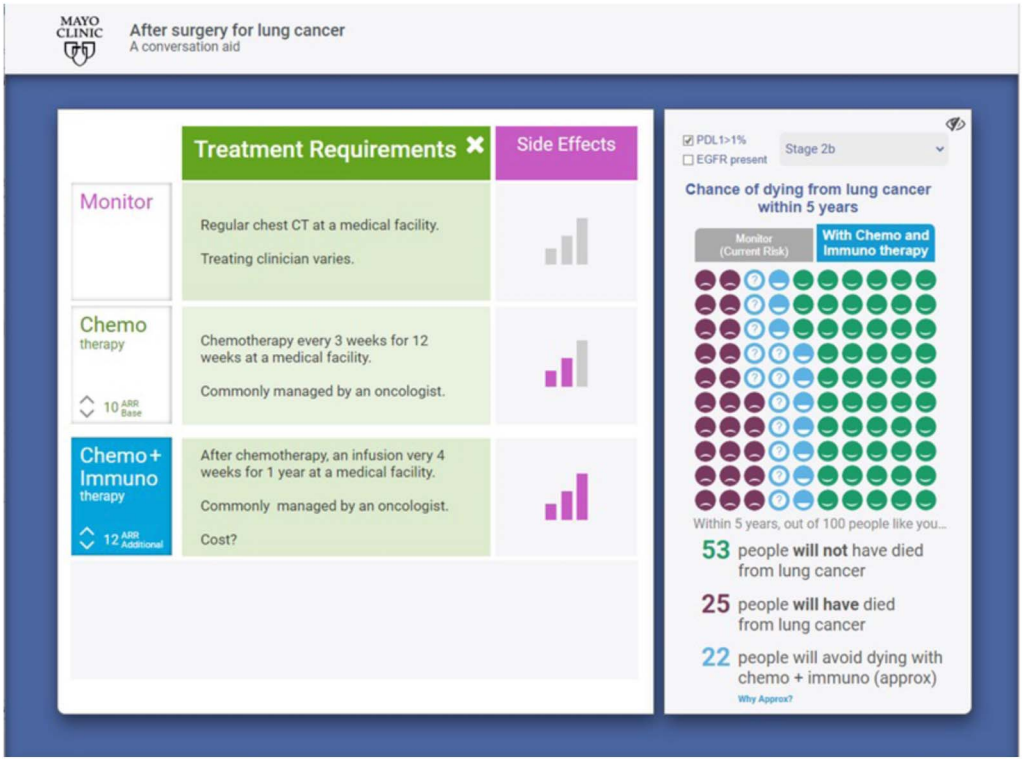

FIG 3. Screen capture of the online shared decision making tool about the treatment of patients with non–small-cell lung cancer after initial surgery. Reproduced with permission. 2023 Mayo Foundation for Research and Education.

results, and causing psychological concerns. Oncologists offering genetic testing can address these issues during counseling, akin to counseling that they routinely undertake for diagnoses and treatments. This counseling should include an in-depth review of important educational concepts and psychosocial issues. For example, patients need to understand that identification of an HCS can lead to tailored treatment for a current cancer and targeted surveillance for future cancers. For example, a woman recently diagnosed with ovarian cancer with an underlying *BRCA1* mutation can be treated with PARP inhibitors, which can improve her survival compared with conventional treatments.[50] Patients identified to have Lynch syndrome become eligible for annual/biennial colonoscopies, beginning at age 20-25 years, in addition to consideration of prophylactic surgeries for women (eg, hysterectomy). These risk-reducing measures lead to earlier detection and prevention, reducing morbidity and mortality in this high-risk population.[51-53] For the patient's relatives, a new diagnosis of an HCS means that they become eligible for genetic testing, with potential ramifications for their own cancer treatments and surveillance.

Another point of concern is the recent transition to larger, more comprehensive genetic tests (eg, large gene panels, genome sequencing); these have increased the likelihood that uncertain results and secondary findings will be revealed, both of which can contribute to challenges in the patients' cancer management and surveillance. Patients should also be informed about the possibility of psychological harms triggered by the genetic testing process or results (eg, distress associated with new cancers, uncertain findings, anxiety and burden around sharing results, guilt of passing on an HCS to children, etc). Adding on to these challenges is the fact that there is often no clear right or wrong decision about whether to pursue genetic testing; the decision is often informed by the patients' values and preferences. As such, it is imperative that patients and their clinicians undertake in SDM, a process that ensures that patients understand all their options and that they incorporate their values into their decision making, to choose the option that is most consistent with their preferences and goals.[54-56]

Despite the increasing importance of SDM, the ability to achieve it has become more challenging as the quality and extent of patient-clinician consultations have decreased over time. Within oncology, this decline can be attributed to multiple factors including the shortage of health care professionals, increased demand for cancer services because of an aging population, and the increasing *industrialization of health care*.[28,57,58] The latter describes the application of management and improvement approaches used in the manufacturing industry and applied to health care delivery.[28] Although designed to enhance standardization, reliability, and efficiency, the industrialization of health care has also exacerbated burnout among clinicians and exhaustion in patients.[28] Moreover, the emergence of the COVID-19

pandemic in early 2020 further exacerbated resource constraints in oncology. The pandemic also transitioned most medical appointments to virtual settings, reducing face-to-face encounters between providers and their patients. Engaging in SDM has become even more challenging with these constraints.[28] As such, new and innovative models of SDM are needed within oncology.

Digital tools are one strategy that can facilitate SDM in patient-clinician consultations and move away from industrialization of health care in oncology.[28] There is evidence from the literature to support this; a recent systematic review found that digital tools can support the many facets of SDM, including increasing patient knowledge, improving psychosocial well-being and engagement, and facilitating decision making.[59] For clinicians, the review found that digital tools provide efficiencies by reducing the time needed with patients and enhancing workflow (eg, less time needed to prep charts).

One example of a digital platform that can support patients and oncologists in delivering genetic testing and SDM is the Genetics Adviser.[60,61] The Adviser is an interactive, patient-facing, digital platform that supports the fundamentals of SDM—by providing both education and psychosocial support at all points in the patients' cancer journey. The Adviser includes interactive educational module that provides in-depth, patient-targeted information. The platform also encompasses values clarification exercises that can help patients explore their values and preferences. Even after patients finish the education modules and values exercises, they have the option to return to the platform at any time, review any materials they completed, and access additional support resources. They can also generate a printable summary that can be easily shared with their circle of care and support (Fig 4). All these steps can be completed at the patients' pace—allowing them to involve their relatives and larger support system in the decision making process. The Adviser's modules and exercises can easily be customized to the oncologists' and patients' needs. They can be used to support patients undergoing genetic testing in mainstreaming practices, patients undergoing rapid genetic testing for treatment purposes, and patients having their tumor profiled, which could reveal germline findings. Moreover, for patients undergoing genetic testing during cancer treatment, the platform provides a flexible resource that can be accessed at any time using multiple modalities (eg, smartphone, desktop, etc) and within any setting (eg, home, work, clinic).

There is considerable evidence that supports the effectiveness of the Genetics Adviser platform in advancing SDM in the oncology setting. For example, one qualitative study found that the Adviser promoted informed dialogue, facilitated preference-sensitive deliberation, and deepened personalization of decisions of patients with cancer.[62] These three functions represent fundamental elements of patient-centered care[63,64] and provide evidence that the platform can facilitate SDM.[65] In addition to facilitating SDM, digital tools like the Genetics Adviser are in line with principles of the *Open Notes Movement*.[66] The real-time sharing of genetic test results through a secure portal reduces uncertainty and promotes transparency. Furthermore, the inclusion of communication through the portal enables asynchronous interaction between the clinician and the patient, reducing the risk of anxiety as the patient awaits their scheduled appointments.[66]

Digital tools such as the Genetics Adviser can educate and empower patients with cancer, giving them agency in their cancer journey. Patients can use the platform to prepare themselves before the initial consultation and then come to a subsequent clinic appointment with their oncologist better prepared and empowered to engage in SDM. As evidence from a recent trial revealed,[67] this will reduce the consultation time that patients need with the health care providers. Therefore, the platform provides an opportunity to have an efficient appointment, reserving the precious and limited clinic time to focus on each patient's unique concerns. Instead of receiving information for the first time at the appointment, patients are coming to the first consultation empowered, having already had a chance to digest the medical information, consult with their circle of care and family, and come prepared with questions. Since the patient has already reviewed the technical and background information, clinicians can focus the time on the patients' specific questions and explore preferences and values to help patients make informed decisions. This indeed was observed in a recent qualitative study, which found that the Genetics Advisor platform increased the degree of deliberation and verbal engagement between patients with cancer and the clinician.[62] This provided the clinician with opportunities to respond to the unique perspectives and experiences of each patient, including clarifying misunderstandings and highlighting personal values, consistent with patient-centered care. Therefore, digital tools can make it easy for oncologists to achieve true SDM with their patients.

Digital tools and other SDM innovations are also facilitating a paradigm shift toward the cocreation of plans of care as a collaborative method to uncover, discover, or invent a response to each patient's problematic situation. This joint work must address the situation as understood by the patient and the clinician, must draw from the best research evidence and from the experience and expertise of the patient and the clinician, and must consider health care resources and the resources that the patient and their caregivers can mobilize to implement the care plan effectively and safely. This places the patient not as a party who must be engaged, involved, or

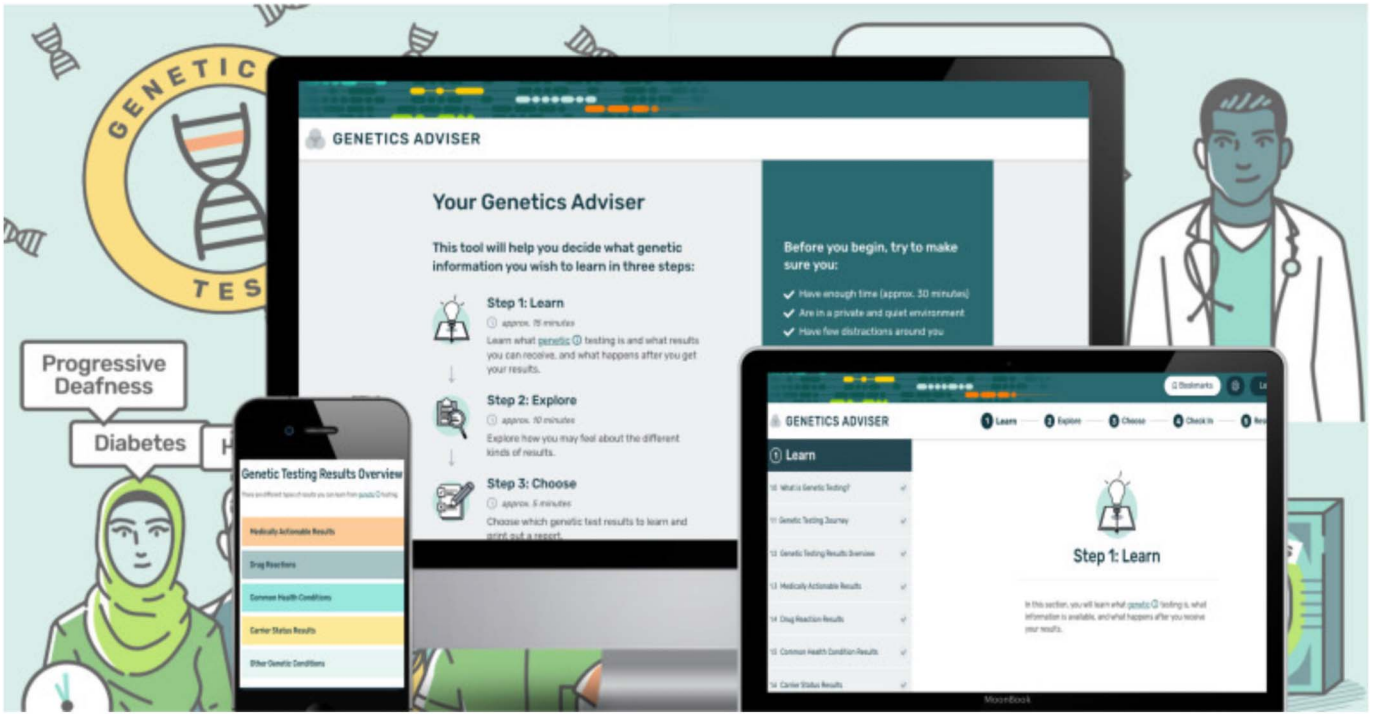

FIG 4. The Genetics Adviser, delivering pretest counseling, waiting period support, and result disclosure via all mobile applications such as smartphones and tablets or computer/desktop applications. Source: PMID: 35487723 with permission.

empowered, but who takes a practical role as an integral codeveloper of plans of care.

SDM FROM A PATIENT PERSPECTIVE

The paradigm guiding interactions between the clinician and the patient is undergoing a sea change. Under the long-prevalent model of paternalism, the doctor was the predominant—if not exclusive!—source of judgment as to the proper course of medical action. But, increasingly, the patient's embodied perspective is being considered when making clinical choices, a shift that respects both an ethical emphasis on autonomy and a pragmatic need to individualize care. Sometimes, SDM is contingent on factors that are known only to the patient and beyond the discernment of quantitative tools at the diagnostician's disposal, obligating an information transfer back and forth for authentic shared governance[68] (M.A.L. is an oncologist living with a hereditary cancer. He has shared his perspective as a patient here: The ASCO Post[69]).

However, it must be acknowledged that even SDM is a term encompassing multiple approaches in need of careful differentiation. In the *informative model*, the clinician provides the patient with all relevant information without recommending a course of action. In the *interpretive model*, the clinician aims to elucidate the patient's values and desires and to help the patient select the available medical intervention that is most congruent with their principles and goals. Although both models require an explanation beyond the dictums of paternalism, the second is a more open exchange of ideas, a bidirectional discourse that does not presuppose an outcome and calls on both sides to adapt to what they are hearing.[70,71] This model is particularly well-suited to decisions in which there is more than one medically reasonable option, and the best plan hinges on patient goals, priorities, values, and preferences.

Implicitly or explicitly, the interpretive model acknowledges the patient as the ultimate stakeholder in their medical outcome. Although fiduciary responsibility is a noble lodestar for minimizing any interference from the physician's own self-interest, even the most empathetic of clinicians does not experience cancer in the same way as those entrusted to their care. Whether the relative abstractions of quality of life or the most clear-cut end point of mortality, it is the patients' own fitness and longevity that are threatened by disease (and, in some cases of iatrogenic harm, its treatment!). As such, they are appropriately positioned as the arbiters *par excellence* as to which metrics matter and which risk/benefit ratios are acceptable, including the ever-present choice of forgoing cancer-directed therapy altogether.

Adding to this modernization of the doctor-patient relationship is the surfeit of digital resources made available to

the public in the information age. Unsurprisingly, among patients with online access, 97% will use the Internet on diagnosis to find information about cancer, with 94% searching on Google. However, the ready yield of results from such a massive search engine carries important caveats; although Google can provide relatively accurate information about etiology and symptoms, it is far less reliable in its descriptions of treatment and prognosis. Efforts to use wording commensurate with average scientific literacy, for example, plain language summaries, are admirable in their inclusivity but carry tradeoffs between reliability and readability. Patients with rarer cancer are particularly vulnerable to the surfacing of misinformation, and even more common diagnoses still require shrewdness about the algorithmic ordering of recommendations for treatment; for instance, searches about specific medications will lead to pharmaceutical websites approximately 20% of the time introducing at least the specter of commercial bias.[72-76]

All told, such patient-initiated digital engagement is both entirely understandable and vulnerable to exploitation or at least misinterpretation. Medical professionals can provide critical assessment of what patients discover during their own online inquiries, vetting search results and separating fact from fiction, meritorious studies from pseudoscience. The once-fallow time between visits now becomes a fertile opportunity for the patient's own preparation asynchronous from their doctor's; they can arrive at their appointments with questions shaped by their independent reading and learn which resources are validated for further self-directed research.[66]

Another potential opportunity for misunderstanding arises through the direct access of laypeople to their *own* test results through patient-facing portals. With the commendable intent of empowering patients, the Open Notes movement embraces transparency and timeliness in the sharing of medical documentation.[77-79] The near-instantaneous delivery of results through secure channels ideally reduces uncertainty and decouples the reporting of a diagnostic test from an in-person visit. Surveys have revealed that many patients taking advantage of this technology feel as if they are more active participants in their treatment when granted this access. They are also more likely to retain the content of in-visit discussions with their doctor, as opposed to purely verbal recall.[80,81] However, if a patient receives the results of a test when an ordering physician is unavailable to help them interpret it, the temporal mismatch may engender more apprehension than if the doctor was explaining the clinical meaning in proper context.[82]

This is especially true of genetic results, which can have life- and family-altering consequences while also being freighted with diagnostic uncertainty, for example, variants of unknown significance. Even the fundamental bifurcation of mutations into somatic and germline defects may be overlooked, with the concern that the former could be extrapolated to a presumption of a hereditary risk. As Martin *et al* frame it, "despite the well-understood benefits of biomarker and genetic testing in precision medicine, uptake remains low… Patients report having limited familiarity with testing terminology and may not be able to accurately explain testing's role in treatment decisions. Patient confusion and lack of understanding is exacerbated by a multiplicity of overlapping terms used in communicating about testing."[83] As a corrective, they propose "democratizing comprehension about precision oncology testing through intentional use of plain language and common umbrella terminology by oncology health care providers and others in the oncology ecosystem may help improve understanding and communication and facilitate shared decision-making about the role of appropriate testing in treatment decisions and other aspects of oncology care."

Outside of cancer medicine, Huntington's disease is often cited as an incisive exemplar of genomic foreknowledge's double-edged sword. The subject's awareness of being the gene carrier of an inexorably progressive and uniformly fatal neurodegenerative disorder can induce intrusive emotions, denial-avoidance behavior, and pessimistic expectancies of the future and adjustment problems.[84] Within oncology, several germline mutations require relatively major surgical interventions early in life to mitigate the risk of oncogenesis. Patients with the CDH1 mutation might have to undergo prophylactic total gastrectomy by the fourth decade, whereas patients with familial adenomatous polyposis have often been considered for colectomy by around the same age. Parents of children with multiple endocrine neoplasia type 2 can even face the wrenching prospect of prophylactic thyroidectomy by their infant's first birthday to avoid medullary thyroid carcinoma arising from proto-oncogenic RET codons 883, 918, or 922.[85,86]

But even the advanced awareness of less lethal predispositions before they become phenotypically evident can pose threats that are harder to quantify. Some medical ethicists posit that contemporary predictive biomedicine has created a *sui generis* diagnostic category: the prepatient. Such persons risk being perceived as ill before they are diseased. As a transitive responsibility, the moral burden of conveying a bad prognosis shifts to the kin, who are then obliged to make decisions about when and how to share or withhold genetic information with other potentially presymptomatic relatives.[87,88]

CONCLUSION

SDM is a method of care on the basis of conversations conducted to arrive at a cocreated plan of care that addresses the problematic situation of each patient. Unhurried

conversations, SDM tools, and collaborative deliberation methods are essential to coproduce care plans with active participation of patients and clinicians. The experience of patients in contributing to care that fits requires access to trustworthy information, experience, and expertise, both within and between clinical encounters. Health care systems that favor the processing of people rather than the care of patients are hostile to methods of patient-centered care, such as SDM, and must be radically reformed if SDM is to become routinized in care.

AFFILIATIONS

[1]Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, ON, Canada
[2]Genomics Health Services Research Program, Li Ka Shing Knowledge Institute, St Michael's Hospital, Unity Health Toronto, Toronto, ON, Canada
[3]Knowledge and Evaluation Research Unit, Mayo Clinic, Rochester, MN
[4]Department of Medical Oncology, Mayo Clinic, Rochester, MN
[5]Division of Gastrointestinal Oncology, Intermountain Healthcare, Salt Lake City, UT
[6]Ontario Institute for Cancer Research, Toronto, ON, Canada

CORRESPONDING AUTHOR

Victor M. Montori, MD, MSc, Mayo Clinic, Plummer 4-402, 200 First St SW, Rochester, MN 55905; e-mail: Montori.victor@mayo.edu.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST AND DATA AVAILABILITY STATEMENT

The following represents disclosure information provided by authors of this manuscript. All relationships are considered compensated. Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. Relationships may not relate to the subject matter of this manuscript. For more information about ASCO's conflict of interest policy, please refer to www.asco.org/rwc.

Konstantinos Leventakos
Consulting or Advisory Role: AstraZeneca (Inst), Targeted Oncology (Inst), OncLive (Inst), Takeda (Inst), Jazz Pharmaceuticals (Inst), Mirati Therapeutics (Inst), Janssen Oncology (Inst), Regeneron (Inst), MJH Life Sciences (Inst), Amgen (Inst)
Research Funding: AstraZeneca (Inst), Mirati Therapeutics (Inst)

Mark A. Lewis
Employment: Medscape
Honoraria: Foundation Medicine
Consulting or Advisory Role: Exelixis, QED Therapeutics, HalioDx, Natera, Ipsen, Novartis, Pfizer, Astellas Scientific and Medical Affairs Inc
Speakers' Bureau: AstraZeneca/Daiichi Sankyo
Other Relationship: Medscape, Foundation Medicine

Yvonne Bombard
Patents, Royalties, Other Intellectual Property: Cofounder of Genetics Adviser

No other potential conflicts of interest were reported.

REFERENCES

1. Chen J, Wang Y: Social media use for health purposes: Systematic review. J Med Internet Res 23:e17917, 2021
2. Kunneman M, Griffioen IP, Labrie NH, et al: Making care fit manifesto. BMJ Evid Based Med 28:5-6, 2023
3. Alston C, Berger Z, Brownlee S, et al: Shared decision-making strategies for best care: Patient decision aids. NAM Perspectives, Discussion Paper, National Academy of Medicine, Washington, D.C., 2014
4. Stiggelbout AM, Van der Weijden T, De Wit MP, et al: Shared decision making: Really putting patients at the centre of healthcare. BMJ 344:e256, 2012
5. Hargraves I, LeBlanc A, Shah ND, et al: Shared decision making: The need for patient-clinician conversation, not just information. Health Aff 35:627-629, 2016
6. Zeballos-Palacios CL, Hargraves IG, Noseworthy PA, et al: Developing a conversation aid to support shared decision making: Reflections on designing anticoagulation choice. Mayo Clin Proc 94:686-696, 2019
7. Kunneman M, Hargraves IG, Sivly AL, et al: Co-creating sensible care plans using shared decision making: Patients' reflections and observations of encounters. Patient Educ Couns 105:1539-1544, 2022
8. Montori VM, Ruissen MM, Hargraves IG, et al: Shared decision-making as a method of care. BMJ Evid Based Med, 2022.
9. Hargraves IG, Montori VM, Brito JP, et al: Purposeful SDM: A problem-based approach to caring for patients with shared decision making. Patient Educ Couns 102:1786-1792, 2019
10. Lippiett KA, Richardson A, Myall M, et al: Patients and informal caregivers' experiences of burden of treatment in lung cancer and chronic obstructive pulmonary disease (COPD): A systematic review and synthesis of qualitative research. BMJ Open 9:e020515, 2019
11. El-Turk N, Chou MS, Ting NC, et al: Treatment burden experienced by patients with lung cancer. PLoS One 16:e0245492, 2021
12. Carrera PM, Kantarjian HM, Blinder VS: The financial burden and distress of patients with cancer: Understanding and stepping-up action on the financial toxicity of cancer treatment. CA Cancer J Clin 68:153-165, 2018
13. Presley CJ, Soulos PR, Tinetti M, et al: Treatment burden of Medicare beneficiaries with stage I non-small-cell lung cancer. JCO Oncol Pract 13:e98-e107, 2017
14. Yabroff KR, Reeder-Hayes K, Zhao J, et al: Health insurance coverage disruptions and cancer care and outcomes: Systematic review of published research. J Natl Cancer Inst 112:671-687, 2020
15. Hoffmann TC, Montori VM, Del Mar C: The connection between evidence-based medicine and shared decision making. JAMA 312:1295-1296, 2014

16. Ruissen MM, Montori VM, Hargraves IG, et al: Problem-based shared decision-making in diabetes care: A secondary analysis of video-recorded encounters. BMJ Evid Based Med 28:157-163, 2023

17. Montori V, Hargraves IG, Breslin M, et al: Careful and kind care requires unhurried conversations. NEJM Catal 5, 2019. https://catalyst.nejm.org/doi/abs/10.1056/CAT.19.0696

18. Hartasanchez SA, Heen AF, Kunneman M, et al: Remote shared decision making through telemedicine: A systematic review of the literature. Patient Educ Couns 105:356-365, 2022

19. Ozanne EM, Noseworthy PA, Cameron KA, et al: Shared Decision Making in the Era of Telehealth: Implications for Practice and Research. Los Angeles, CA, Sage Publications, 2020

20. Burbury K, Wong ZW, Yip D, et al: Telehealth in cancer care: During and beyond the COVID-19 pandemic. Intern Med J 51:125-133, 2021

21. Boehmer KR, Dobler CC, Thota A, et al: Changing conversations in primary care for patients living with chronic conditions: Pilot and feasibility study of the ICAN Discussion Aid. BMJ Open 9:e029105, 2019

22. Boehmer KR, Hargraves IG, Allen SV, et al: Meaningful conversations in living with and treating chronic conditions: Development of the ICAN discussion aid. BMC Health Serv Res 16:1-9, 2016

23. Shared decision making tools. Knowledge and evaluation research unit. Mayo Clinic. http://carethatfits.org/tools

24. Breslin M, Mullan RJ, Montori VM: The design of a decision aid about diabetes medications for use during the consultation with patients with type 2 diabetes. Patient Educ Couns 73:465-472, 2008

25. Volk RJ, Llewellyn-Thomas H, Stacey D, et al: Ten years of the International Patient Decision Aid Standards Collaboration: Evolution of the core dimensions for assessing the quality of patient decision aids. BMC Med Inform Decis Mak 13:S1, 2013 (suppl 2)

26. Brito JP, Moon JH, Zeuren R, et al: Thyroid cancer treatment choice: A pilot study of a tool to facilitate conversations with patients with papillary microcarcinomas considering treatment options. Thyroid 28:1325-1331, 2018

27. Montori V: Why We Revolt: A Patient Revolution for Careful and Kind Care. Rochester, MN, Patient Revolution, 2017

28. Montori VM, Allwood D: Careful, kind care is our compass out of the pandemic fog. BMJ 379:e073444, 2022

29. Allwood D, Koka S, Armbruster R, et al: Leadership for careful and kind care. BMJ Lead 6:125-129, 2022

30. Heath I, Montori VM: Responding to the crisis of care. BMJ 380:p464, 2023

31. Lindor NM, McMaster ML, Lindor CJ, et al: Concise handbook of familial cancer susceptibility syndromes—Second edition. J Natl Cancer Inst Monogr 38:1-93, 2008

32. Petrucelli N, Daly MB, Pal T: *BRCA1*- and *BRCA2*-Associated Hereditary Breast and Ovarian Cancer. 1998 Sep 4 [updated 2022 May 26]. In Adam MP, Mirzaa GM, Pagon RA, Wallace SE, Bean LJH, Gripp KW, Amemiya A, (eds). GeneReviews®[Internet]. Seattle, WA, University of Washington, Seattle, 1993–2023

33. Claus EB, Schildkraut JM, Thompson WD, et al: The genetic attributable risk of breast and ovarian cancer. Cancer 77:2318-2324, 1996

34. Kuchenbaecker KB, Hopper JL, Barnes DR, et al: Risks of breast, ovarian, and contralateral breast cancer for BRCA1 and BRCA2 mutation carriers. JAMA 317:2402-2416, 2017

35. Mavaddat N, Peock S, Frost D, et al: Cancer risks for BRCA1 and BRCA2 mutation carriers: Results from prospective analysis of EMBRACE. J Natl Cancer Inst 105:812-822, 2013

36. Consortium BCL: Cancer risks in BRCA2 mutation carriers. J Natl Cancer Inst 91:1310-1316

37. Lynch HT, Casey MJ, Snyder CL, et al: Hereditary ovarian carcinoma: Heterogeneity, molecular genetics, pathology, and management. Mol Oncol 3:97-137, 2009

38. Brose MS, Rebbeck TR, Calzone KA, et al: Cancer risk estimates for BRCA1 mutation carriers identified in a risk evaluation program. J Natl Cancer Inst 94:1365-1372, 2002

39. Levine DA, Argenta PA, Yee CJ, et al: Fallopian tube and primary peritoneal carcinomas associated with BRCA mutations. J Clin Oncol 21:4222-4227, 2003

40. Reiner AS, Robson ME, Mellemkjær L, et al: Radiation treatment, ATM, BRCA1/2, and CHEK2*1100delC pathogenic variants and risk of contralateral breast cancer. J Natl Cancer Inst 112:1275-1279, 2020

41. Senter L, Clendenning M, Sotamaa K, et al: The clinical phenotype of Lynch syndrome due to germ-line PMS2 mutations. Gastroenterology 135:419-428, 2008

42. Baglietto L, Lindor NM, Dowty JG, et al: Risks of Lynch syndrome cancers for MSH6 mutation carriers. J Natl Cancer Inst 102:193-201, 2010

43. Bonadona V, Bonaïti B, Olschwang S, et al: Cancer risks associated with germline mutations in MLH1, MSH2, and MSH6 genes in Lynch syndrome. JAMA 305:2304-2310, 2011

44. Giardiello FM, Allen JI, Axilbund JE, et al: Guidelines on genetic evaluation and management of Lynch syndrome: A consensus statement by the US Multi-society Task Force on colorectal cancer. Am J Gastroenterol 109:1159-1179, 2014

45. Dominguez-Valentin M, Sampson JR, Seppälä TT, et al: Cancer risks by gene, age, and gender in 6350 carriers of pathogenic mismatch repair variants: Findings from the Prospective Lynch Syndrome Database. Genet Med 22:15-25, 2020

46. Daly MB, Pal T, Berry MP, et al: Genetic/Familial High-Risk Assessment: Breast, Ovarian, and Pancreatic, Version 2.2021, NCCN Clinical Practice Guidelines in Oncology. J Natl Compr Canc Netw 19:77-102, 2021

47. Berliner JL, Fay AM, Cummings SA, et al: NSGC practice guideline: Risk assessment and genetic counseling for hereditary breast and ovarian cancer. J Genet Couns 22:155-163, 2013

48. Robson ME, Bradbury AR, Arun B, et al: American Society of Clinical Oncology policy statement update: Genetic and genomic testing for cancer susceptibility. J Clin Oncol 33:3660-3667, 2015
49. Manahan ER, Kuerer HM, Sebastian M, et al: Consensus guidelines on genetic testing for hereditary breast cancer from the American Society of Breast Surgeons. Ann Surg Oncol 26:3025-3031, 2019
50. Friedlander M, Matulonis U, Gourley C, et al: Long-term efficacy, tolerability and overall survival in patients with platinum-sensitive, recurrent high-grade serous ovarian cancer treated with maintenance olaparib capsules following response to chemotherapy. Br J Cancer 119:1075-1085, 2018
51. Rebbeck TR, Friebel T, Lynch HT, et al: Bilateral prophylactic mastectomy reduces breast cancer risk in BRCA1 and BRCA2 mutation carriers: The PROSE Study Group. J Clin Oncol 22:1055-1062, 2004
52. Marchetti C, De Felice F, Palaia I, et al: Risk-reducing salpingo-oophorectomy: A meta-analysis on impact on ovarian cancer risk and all cause mortality in BRCA 1 and BRCA 2 mutation carriers. BMC Womens Health 14:150, 2014
53. de Vos tot Nederveen Cappel WH, Järvinen HJ, Lynch PM, et al: Colorectal surveillance in Lynch syndrome families. Fam Cancer 12:261-265, 2013
54. Albada A, van Dulmen S, Ausems MG, et al: A pre-visit website with question prompt sheet for counselees facilitates communication in the first consultation for breast cancer genetic counseling: Findings from a randomized controlled trial. Genet Med 14:535-542, 2012
55. Wang C, Gonzalez R, Milliron KJ, et al: Genetic counseling for BRCA1/2: A randomized controlled trial of two strategies to facilitate the education and counseling process. Am J Med Genet A 134A:66-73, 2005
56. Montori VM, Ruissen MM, Hargraves IG, et al: Shared decision-making as a method of care. BMJ Evid Based Med 10.1136/bmjebm-2022-112068 [epub ahead of print on December 2, 2022]
57. Limb M: Shortages of radiology and oncology staff putting cancer patients at risk, college warns. BMJ 377:o1430, 2022
58. Erikson C, Salsberg E, Forte G, et al: Future supply and demand for oncologists: Challenges to assuring access to oncology services. JCO Oncol Pract 3:79-86, 2007
59. Lee W, Shickh S, Assamad D, et al: Patient-facing digital tools for delivering genetic services: A systematic review. J Med Genet 60:1-10, 2023
60. Shickh S, Hirjikaka D, Clausen M, et al: Genetics adviser: A protocol for a mixed-methods randomised controlled trial evaluating a digital platform for genetics service delivery. BMJ Open 12:e060899, 2022
61. Genetic Advisor Application. https://www.geneticsadviser.com/
62. Shickh S, Rafferty SA, Clausen M, et al: The role of digital tools in the delivery of genomic medicine: Enhancing patient-centered care. Genet Med 23:1086-1094, 2021
63. Epstein RM, Street RL: Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. NIH Publication No. 07-6225. Bethesda, MD, National Cancer Institute, NIH publication No. 07-6225, 2007
64. Armstrong MJ, Shulman LM, Vandigo J, et al: Patient engagement and shared decision-making: What do they look like in neurology practice? Neurol Clin Pract 6:190-197, 2016
65. Schmidlen T, Sturm AC, Hovick S, et al: Operationalizing the reciprocal engagementmodel of genetic counseling practice: A framework for the scalable delivery of genomic counseling and testing. J Genet Couns 27:1111-1129, 2018
66. Lewis MA, Bustillo D: Patient perspective: Importance and how to elicit. Med Clin North Am 106:569-576, 2022
67. Bombard Y, Clausen M, Shickh S, et al: Effectiveness of the Genomics ADvISER decision aid for the selection of secondary findings from genomic sequencing: A randomized clinical trial. Genet Med 22:727-735, 2020
68. Faiman B, Tariman JD: Shared decision making: Improving patient outcomes by understanding the benefits of and barriers to effective communication. Clin J Oncol Nurs 23:540-542, 2019
69. Piana R. Living with hereditary cancer, oncologist Mark A. Lewis, MD, shares his experiences on social media to assist others. https://ascopost.com/issues/july-25-2022/living-with-hereditary-cancer-oncologist-mark-a-lewis-shares-his-experiences-on-social-media-to-assist-others/
70. Emanuel EJ, Emanuel LL: Four models of the physician-patient relationship. JAMA 267:2221-2226, 1992
71. Kane HL, Halpern MT, Squiers LB, et al: Implementing and evaluating shared decision making in oncology practice. CA Cancer J Clin 64:377-388, 2014
72. Grewal P, Alagaratnam S: The quality and readability of colorectal cancer information on the internet. Int J Surg 11:410-413, 2013
73. Chang K, Berthelet E, Grubbs E, et al: Websites, websites everywhere: How thyroid cancer patients use the internet. J Cancer Educ 35:1177-1183, 2020
74. De Groot L, Harris I, Regehr G, et al: Quality of online resources for pancreatic cancer patients. J Cancer Educ 34:223-228, 2019
75. Kuenzel U, Monga Sindeu T, Schroth S, et al: Evaluation of the quality of online information for patients with rare cancers: Thyroid cancer. J Cancer Educ 33:960-966, 2018
76. Beaton C, Codd RJ, Holland PA, et al: Evaluation of the quality and accuracy of information regarding aromatase inhibitors available on the internet. Breast J 14:366-368, 2008
77. Blease C, McMillan B, Salmi L, et al: Adapting to transparent medical records: International experience with “open notes”. BMJ 379:e069861, 2022
78. Rahimian M, Warner JL, Salmi L, et al: Open notes sounds great, but will a provider’s documentation change? An exploratory study of the effect of open notes on oncology documentation. JAMIA Open 4:ooab051, 2021
79. Salmi L, Dong ZJ, Yuh B, et al: Open notes in oncology: Patient versus oncology clinician views. Cancer Cell 38:767-768, 2020

80. Talcott JA, Aharonoff G, Bezuhly M, et al: Discussions of cancer screening: What do physicians say, what do patients hear, and how much shared decision making occurs? J Clin Oncol 34, 2016 (suppl 7; abstr 180)

81. Stewart MA: Effective physician-patient communication and health outcomes: A review. CMAJ 152:1423, 1995

82. Austin EJ, Kilgore MR, Ko CW, et al: Multi-pilot implementation experiences of patient-centered pathology reports: Lessons learned for the advancement of patient-centered tools for cancer decision-making. Cancer Causes Control 34:399-406, 2023

83. Martin NA, Tepper JE, Giri VN, et al: Adopting consensus terms for testing in precision medicine. JCO Precis Oncol 5:1563-1567, 2021

84. Tibben A, Duivenvoorden HJ, Niermeijer MF, et al: Psychological effects of presymptomatic DNA testing for Huntington's disease in the Dutch program. Psychosom Med 56:526-532, 1994

85. Hoskins C, Tutty E, Purvis R, et al: Young people's experiences of a CDH1 pathogenic variant: Decision-making about gastric cancer risk management. J Genet Couns 31:242-251, 2022

86. Sarvepalli S, Burke CA, Monachese M, et al: Natural history of colonic polyposis in young patients with familial adenomatous polyposis. Gastrointest Endosc 88:726-733, 2018

87. Gavara GI, Ponce Marco JL, Belda Ibañez T, et al: The optimal age for performing surgery on patients with MEN 2B syndrome. Oncol Lett 2:929-930, 2011

88. Konrad M: Predictive genetic testing and the making of the pre-symptomatic person: Prognostic moralities amongst Huntington's-affected families. Anthropol Med 10:23-49, 2003