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Decision Making About Cancer Screening: An Assessment of the State of the Science and a Suggested Research Agenda

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Introduction

Broad participation in screening is key to cancer prevention and early detection. Unfortunately, screening rates are low for many modalities. At its core, successful screening involves an individual deciding to take action (e.g., completing self-exams, scheduling appointments). Therefore, the science of decision making is central to understanding and increasing screening adherence. In this commentary, we (members of ASPO's Behavioral Oncology Interest Group) consider the state of the science on screening decision making and recommend research directions to advance the field. We address three key areas: implications of the nature of screening behavior for understanding decision making, expanding current decision-making theories to consider other influences on behavior, and using decision science findings to develop effective interventions.

Considering Features of Screening Behavior

Choices Among Multiple Screening Options

For some cancers, particularly colorectal cancer, multiple screening options exist. Current guidelines recommend that clinicians offer multiple options and invite people to choose (1-3). Given that preferences differ, offering patients the option to choose might enhance uptake (4). However, multiple options may cause confusion (5,6). This confusion may contribute to low screening rates (7). Given the issues related to multiple screening options, issues of how to present choices and prevent confusion about screening options are of great import. This importance will likely grow as new screening tests are developed.

In terms of decision science, multiple options and the resulting complexity of screening decisions creates a need to enhance informed decision making and create better matches between patient preferences and screening options (8,9). Such opportunities might translate into greater adherence. Recent research has examined innovative approaches to identifying patient preferences. For example, conjoint analysis approaches have been used to elicit preferences (8,9) and to assist individuals in identifying a screening strategy consistent with those preferences. Conjoint analysis works by presenting competing alternatives or outcome scenarios and asking respondents to rank or rate them. The approach has been used to assess the perceived value of genetic testing (10), the personal utility of genomic information (11), and processes in shared decision making (12-15). Conjoint analysis allows assessment of the absolute and relative importance of choice attributes as well as how people utilize attribute judgments to make decisions. Combining screening information with such preference elicitation strategies may be an elegant decision aid strategy (16,17) to promote informed screening decisions and more effective communication with providers (18) about screening options.

A second area to consider is comparative effectiveness research, a domain which has gained prominence in recent years as a tool for controlling medical expenditures. Such work has a potential impact on policy, choice, and personalized medicine (19). Given this fact and the aim of assessing effectiveness of treatment and prevention alternatives, knowledge of how individuals decide among multiple options may prove to be a valuable contribution to comparative effectiveness efforts (20). This may be especially relevant given that offering a smaller number of screening options may create missed opportunities for screening given individuals' preferences, barriers to screening, or non-availability of certain procedures in some areas.

Screening as a Population-Level Strategy

By definition, screening is a population-level enterprise. As such, the benefits and risks of screening tests are measured as properties of population groups (21). The screening goal of reducing cancer morbidity and mortality leads to an objective of testing large numbers of individuals in order to distinguish the small number of people who may have the disease from the much larger group who likely do not (22). Consequently, few individuals derive direct, individual benefit from screening; benefits accrue to the group, not the individual. However, most people fail to view screening in these population-based terms because epidemiologic risk is not intuitive to most individuals. People are therefore likely to define screening benefits in terms of their personal chances of averting disease/death rather than at the population level (23). Added to this conceptual complexity, all screening tests have performance limitations (e.g., false positives, false negatives) which influence effectiveness and affect willingness to participate.

The cognitive challenges associated with conceptualizing screening as a population-level strategy have not been well explored; decision research could aid understanding of how individuals consider population-level risks and benefits and how to best create interventions targeting such perceptions. Understanding how patients, clinicians, policy makers and insurers make decisions for screening in light of these parameters is critical if we are to develop a normative model for screening decisions.

From a policy perspective, when there is strong evidence of a population benefit (e.g., cervical cancer screening), a public health approach to promote test uptake is appropriate. In such cases, participation in screening should still be voluntarily decided by the individual; however, this informed but voluntary decision ideal may be difficult to achieve when there is overwhelming public acceptance and support for tests (24). When evidence for population benefits is insufficient (e.g., prostate screening), public health approaches may be harder to justify. It is under these circumstances that the science of decision making may have its greatest application. This is especially relevant in countries where decisions to offer screening tests are not made by a central authority (e.g., the U.S.) and consequently scientific evidence of population benefit is not necessarily a prerequisite for test availability. While clinicians decide which tests to recommend and patients decide which tests to have, screening decisions are often driven by reimbursement policies and availability may be driven by market forces. Examination of how such factors influence screening decisions might suggest new routes to encouraging screening.

The tension between policy to promote uptake of effective cancer screening tests and individual decisions to participate in screening is unresolved (25). Future research that elucidates a conceptual model to integrate behavioral constructs at each step of the population screening algorithm with decision-making science that illuminates the choice points for the individual patient and provider would advance this field.

Expanding Screening Decision-Making Models

Affective Influences on Screening Decisions

Much of the focus in informed decision making about cancer screening has been on cognitive processes, especially using expected-utility weighing of the strengths and drawbacks of various options to decide whether to undergo screening or to decide among multiple screening options (26,27). Affect – both negative (e.g., fear, embarrassment) and positive (e.g., satisfaction) – likely plays a key role in decisions about uptake and maintenance. To date, however, its role is understudied.

Affect may influence decisions through a variety of mechanisms. Importantly, fear, worry, and other aspects of negative affect have long been recognized as an influence on behavior (28,

29). Such negative affect is a key component of cancer risk perception, an important determinant of behavior (30-33). In some models relating risk perception to behavior, affect and cognition are seen as two parallel processes in decision making, with behavior change resulting when increased negative affect (e.g., fear) is coupled with a cognitively-based plan for reducing health threats (34-36). These models have been successfully applied to cancer screening (37-39). Another influence of negative affect is as an inhibitor or barrier of screening behavior in the Health Belief Model (e.g., 40, for a review see 41). Finally, newer work has examined a variety of other affective influences including embarrassment about screening tests (42-44), anticipated regret for not engaging in preventive behavior (32), and body image concerns (45). Positive affect (e.g., satisfaction with behavior change) influences preventive behavior maintenance (46-48), but its role has not been examined for cancer screening.

In summary, there is evidence that affect plays an important role in decisions about screening, is separate and distinct from cognitions, and can have unique effects on behavior (32,49-51). The role of affect may be especially critical when screening tests have suboptimal sensitivity and specificity (e.g., ovarian cancer), may lead to unclear treatment options (e.g., prostate cancer), or require choice among multiple screening options (e.g., colorectal cancer). For example, elevated worry has been associated with risk overestimation and subsequent inappropriate utilization of ovarian cancer screening (52). Important research needs include clarifying the mechanisms by which affect drives screening decisions, delineation of whether constructs such as anticipated regret are best conceptualized as affect versus cognition, whether the association between affect and screening uptake differs from that with maintenance, and whether models of affective influences on decision making developed in other health-related domains generalize to screening behaviors. Accordingly, addressing the diverse roles of affect in screening decision making is an understudied, fruitful area for further exploration.

Role of System and Policy Factors

Facilitating screening and subsequent care requires a “fit” among patient-level (e.g., beliefs, knowledge), policy-level (e.g., guidelines, third-party payer eligibility), and system-level factors (e.g., health care delivery). Although recent policy changes have begun to address system-level barriers (e.g., mandated Medicare/Medicaid screening coverage), the complexity of policy and systems factors significantly impacts screening.

In particular, five system-level factors related to “access to care” (53) influence screening behavior: 1) Availability: Are there sufficient facilities, specialized services, and personnel to meet the community's needs? 2) Accessibility: How easily can available resources be accessed given transportation systems, distance, etc.? 3) Accommodation: How do providers structure services (e.g., hours, transportation assistance)? Is that structure seen as appropriate by patients? 4) Affordability: How are services priced? How is payment method taken into account? How do patients balance costs and benefits of services with ability to pay? 5) Acceptability: What are the reactions of patients to provider (e.g., demographics, beliefs), facility (e.g., type, location), and screening procedure (e.g., preparation) characteristics? What are providers' reactions to patient characteristics (e.g., SES, beliefs about willingness to screen)?

These dimensions are intertwined and reveal the inherent complexity of system-level factors. Such complexity raises multiple barriers to screening compliance. For example, trust in the provider (acceptability) may crucially influence whether provider recommendations lead to learning about and considering screening, whereas lack of accessibility or affordability create downstream barriers.

Overall, system-level barriers call for system-level changes (e.g., health care reform; culturally appropriate navigational programs 54). Greater sensitivity and research is needed to achieve

“fit” between patient-level factors and the dimensions of access. For example, what policies can address financial barriers and are such policies effective? What communication channels are best for education addressing systems factors? How do we tailor or target messages to address these factors? How do we address low trust in the medical establishment, especially among certain racial groups (e.g., African-Americans)? How do low trust and limited service availability combine to create barriers in disadvantaged communities? What are the limits of accommodations that providers and patients are willing to make to facilitate screening? Addressing these and other questions are paramount to increase screening, especially in underserved and special populations.

Integrating Decision Making in Screening Programs and Intervention Development

Issues Related to Genetic Screening

Recent advances in genetic tests for cancer risk raise important issues. Such genetic risk testing is distinct from most cancer screening tests in that it is a prevention technique and, although done at the level of the individual patient, has direct health implications for the broader family unit. Two issues are of particular interest. The first concerns provider-centered versus patient-centered decision-making approaches. A key focus in research in this area is provider-centered work related to competencies for how to prepare patients and debrief them regarding results (55,56). On the other hand, much of the practice in this area is increasingly patient-centered, focusing on informed decision making, education to allow for appropriate risk perception, patient-centered coping with risk information, and use of patient-reported outcomes to assess decision-making outcomes (57-59). The integration of these two areas is an area of needed further research. In particular, this consideration of integration of patient and provider approaches should consider the important issue of health literacy (60,61). Many patients have difficulty understanding complex medical, numerical, or genetic information, so presenting information in a way that is understandable and facilitates decision making is a critical need (62). The rapid pace of advances in cancer genetics and genomics mean that attention to health literacy issues and their role in decision making is critically important.

A second key area concerns how patients interpret and respond to genetic risk tests and how those tests impact subsequent screening decisions. A majority of individuals receiving results indicating increased risk engage in subsequent screening, although the follow-up rate is far below 100% for some cancer genetic tests (63-65). However, individuals who have undergone genetic counseling and testing do not always follow screening recommendations (66). Some individuals who receive a favorable result (i.e., no increased risk) express relief and perceive their risk for the cancer to be almost non-existent. Based on this, they decide not to follow through with standard screening recommendations. On the other hand, those whose tests results do indicate increased risk sometimes face difficulty making decisions about further screening and/or risk-reducing surgery (67). Research is needed to understand decisions arising from genetic test results, regardless of mutation carrier status (68,69), and further research into best practices for presenting genetic/genomic information so as to facilitate informed decisions is needed.

Decision Science and Intervention Development

Screening decisions shape important outcomes for individuals. Errors in making health care decisions related to screening can be costly, resulting in unnecessary screening or treatment, or leading to delayed diagnosis and subsequent increased morbidity and/or mortality. Interventions must be geared toward helping individuals make optimal decisions. Such interventions should increase knowledge, decrease decisional conflict over time, be sensitive to issues of numeracy and literacy, allow for decisions that are stable in the face of minor

changes in context (e.g., framing effects), and incorporate the role of affect and of both deliberative and intuitive decisional processes in decision making.

Two areas of particular interest and research attention over the past decade have involved the formal use of decision aids and theory-based intervention tailoring, including culturally sensitive and systems approaches for underserved populations (e.g., access to care) (70). The latter are critically important given the growing trend of population-specific screening guidelines (e.g., those considered for colon cancer screening in African-Americans 71,72).

These two areas of decision-making intervention research have already shown great promise. Further research needs include addressing the following questions: How might the role of deliberative and intuitive decision making be determined and integrated within the context of decision aid interventions? What are the best ways to integrate these systems by providing information in a way that may maximize optimal decision making? Based upon the needs for culturally sensitive and tailored interventions, how and in what situations might interventions be geared to moving individuals to more deliberative or intuitive thinking in order to enhance optimal decision making?

Summary

The complexity of screening behavior and the numerous influences on adherence with recommendations raise a number of issues for understanding screening decisions and using that knowledge to inform interventions and public policy. Research to advance such understanding, such as that recommended in this commentary, is critical if we are to advance the public health goal of using screening to reduce cancer mortality.

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