Research Prioritization Topic Brief

Topic 1: “Communicating risks for minorities or low literacy patients”

Compare the effectiveness of physician/patient communication models on improving risk communication in racial and ethnic minorities, patients with low literacy, or medically underserved populations.

PCORI Scientific Program Area: Addressing Health Disparities

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Introduction
This topic brief focuses on physician/patient communication models for improving risk communication in adult populations, with an emphasis on racial and ethnic minorities, patients with low literacy, or medically underserved populations. Risk communication involves information such as potential risks, benefits, how to avoid harm, and how to improve self-care—all of which are critical to patients’ ability to make informed healthcare choices.

Risk communication involves various components, including: (1) who communicates information; (2) how information is communicated (verbally, visually, with supporting materials, collaboratively); (3) how much and what kind of information is communicated; (4) where information is communicated (setting); and (5) the context of the communication (values, circumstances, preferences). Current research mainly focuses on communication related to disease, condition, or behavior, rather than highlighting how communication works within various groups of people, such as those with lower literacy, racial/ethnic minorities, and the underserved. Although limited, there are resources that describe guidelines and recommendations that can be incorporated into practice.

Burden on Society
Poor risk communication leads to less informed choices, less satisfaction, the potential for poor health outcomes, as well as overutilization and underutilization of health services. Individuals with low
literacy, racial/ethnic minorities, the medically underserved, and non–English-speaking people are more likely to experience health disparities\(^7,8\) and are more likely to have difficulty understanding, expressing, and acting on health information.\(^2,9,10\)

Nearly half of the US population has low or limited health literacy skills. Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”\(^11\) Examples of skills related to health literacy include evaluating information, analyzing risks and benefits, and interpreting test results.\(^7\) Oral language skills also factor into good communication.\(^7\) Approximately 36% of adults in the United States have limited health literacy, and only 12% of the population has a proficient health literacy level.\(^10\) Those who did not graduate from high school; speak limited English; or are Hispanic, black, poor, or older (65+) are most likely to have limited health literacy.\(^10\) Health literacy potentially explains racial/ethnic health disparities,\(^4\) and there is some evidence that limited numeracy skills may also contribute to disparities in health outcomes.\(^5\)

Limited access to care due to uninsurance is a barrier to risk communication. The medically underserved have barriers to healthcare access and are defined as uninsured, underinsured, or poor with insurance.\(^8\) Twenty-one percent of the civilian, non-institutionalized US population (18–64) was uninsured based on data from the 2011 National Health Interview Survey, while 40% of poor and 40% of near-poor adults aged 18–64 lacked coverage at the time of interview. When examining by race-ethnicity, Hispanic persons were most likely to be uninsured (more than 25%) compared to their white counterparts.\(^12\)

Limited English proficiency is a barrier to appropriate risk communication. Language is an important barrier to good risk communication. According to the US Census Bureau, 20% of the US population aged 5 and older speak a language other than English inside the home, and, of those households, 24% report speaking English “not well” or “not at all.”\(^13\) Over 60% of these households speak Spanish.

**Evidence that Addresses Risk Communication**
Sparse and diverse literature exists that directly addresses risk communication among racial and ethnic minorities and the medically underserved. Adults with limited literacy skills have trouble with basic health information and understanding risks of treatments or medical care,\(^14,15\) and they are more likely to have poor health outcomes.\(^5\) Low health literacy appears to limit the quality of health decision making\(^16,17\) and patients’ ability to act on information concerning treatment risks and benefits,\(^18\) particularly among older adults.\(^18\) Although patient participation is essential in risk communication, it has been shown that individuals with lower functional literacy perceive their role in shared decision making as consenting to a treatment recommendation, whereas younger patients,\(^19\) and those with higher education and functional literacy,\(^17,19\) are more likely to view decision making as a collaborative process.

There is some evidence that poor communication of risk affects patients. A study among newly diagnosed patients with lung cancer found that the decision not to pursue surgery—the only reliable treatment for cure—was associated with poor patient-physician communication. This contributed to an 11% difference between black patients, who were less likely to pursue surgery, and white patients, who were more likely.\(^20\) A study of low-income underinsured/uninsured women with heart disease risk factors found that, after one year, 66% could not recall being told their condition (e.g., high blood
pressure, high cholesterol, or diabetes). Authors attributed this to a provider-patient communication gap or to difficulties in retaining health information. Those with the lowest levels of education were the least likely to recall their condition.

Evidence addressing risk communication relevant to race and ethnicity is limited and focuses on issues such as cultural competency, patient and provider concordance (social concordance, racial/ethnic concordance), trust, and the role of ethnic communities in influencing risk perceptions. A single study comparing effectiveness of patient-centered collaborative care verses standard care among African American patients in primary care settings found similar improvements in clinical outcomes and better ratings of care for those with patient-centered collaborative care. One study found that African American patients’ perceptions of a physician’s race impacts patients’ accuracy in risk perceptions, where participants with a racially discordant physician had less accurate risk perceptions, independent of other factors, such as trust in the provider, engagement with the healthcare system, or attention during the encounter. Finally, two studies note the role of social networks and communities as having an influential role in decision making beyond the patient-physician relationship.

Options for Addressing the Issue

The literature on risk communication is developing and offers limited information on communication among populations at greatest risk of poor health outcomes. Systematic reviews on risk communication focus on a small number of content areas: (1) communication design, such as how to quantitatively present risk; (2) how people process information, and whether it is preferable to present detailed versus limited information; and (3) the method of communication, such as comparing verbal versus visual presentation of risk. The literature focuses on outcomes such as informed choice, decisional clarity, decision making in accordance with values, and implications on actual behavior (such as cancer screening or smoking cessation).

The evidence to support the best interventions for improving risk communication—such as, type, format, content—is inconsistent. Much of the evidence on the best approaches to improve risk communication focuses on the format for populations who share common health conditions or procedures, and not necessarily on populations with common demographic characteristics. This may provide a useful foundation for new research testing formats among populations at high risk for health disparities. One synthesis of existing empirical evidence, and consultations with experts in risk communication, could not recommend a clear communication format for presenting risk (verbal, visual, and numeric) because of: (1) lack of consistency in testing formats using the same outcomes, (2) lack of strongly designed studies comparing formats, and (3) lack of theoretical progress in explaining why one format should work better in a specific context than others.

One promising communication tool—decision aids—has been shown to increase patient knowledge, encourage more active patient involvement in decision making, decrease levels of anxiety, and lead to informed values-based decisions. However, less is known about their effect on adherence, consultation length, patient-provider communication, and use with low literacy populations. This is an area where there is a need for further research.

Motivational interviewing is a technique recommended by the Centers for Disease Control and Prevention (CDC) to promote shared decision making among Medicare beneficiaries. This technique...
echoes risk communication recommendations, where information is communicated in a personalized and collaborative manner and repeated back by the patient to make sure it is understood (“teach-back”).35,36

**Potential for New Information to Improve Care and Patient-Centered Outcomes Rapidly**

Although risk communication and shared decision making align well with patient-centered outcomes research and the principles of patient-centered medical homes, we need to learn more about how to create and disseminate strategies specifically for populations at greatest risk of poor health outcomes. Additionally, more knowledge is needed around implementing these strategies in clinical practice. One challenge to shared decision making is inadequate communication. Healthcare professional training on risk communication and shared decision making has been shown to be effective in building patient-centered skills among providers, though effects on patient satisfaction, health behavior, and health status are mixed according to one systematic review,37 while another review says provider training on shared decision making “may be important,”33 and the adoption of shared decision making into clinical practice deserves further investigation.

**New Directions for Research**

Research on this topic will remain current for several years. Researchers note multiple areas for further investigation, including exploring the effectiveness of different formats for presenting of probability information regarding health decisions,38 as well as exploring the best methods for communicating risk to racial/ethnic minorities, patients with low literacy, or the medically underserved, in daily clinical practice.39 Other areas include how to prioritize risks and decisions relative to others for best overall health and examination into other factors, such as personal context, social networks, or spiritual beliefs, and how they contribute to risk communication and decision making.
References

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