NCCN National Comprehensive Cancer Network®

Better Information for Better Outcomes

Policy and Practice Strategies for Patient Education

People impacted by cancer across various demographics face challenges when trying to find reliable, digestible information about their diagnosis and treatment, opening the door for misinformation or disinformation.

The following information was gathered through an environmental scan of 18 patient advocates representing 13 different organizations, as well as the corresponding NCCN Patient Advocacy Summit featuring best practice presentations and panel discussions by the multi-stakeholder, multi-disciplinary cancer care community.

Challenges Faced by Patients

- Health education materials are often not developed at an accessible health literacy level, which can lead to misunderstanding.
- At diagnosis, shock experienced by patients may impair ability to process information/medical advice.
- Providers have limited time to address health information needs.
- Providers receive limited training on how to communicate effectively, which can reduce trust, limit shared decision-making, and impact treatment adherence.

According to the Barbara Bush Foundation for Family Literacy, 54% of Americans read below a 6th grade level[1].

Barriers to High-Quality Medical Information

- Lack of trust in the medical community can impact the delivery of effective cancer care and screening.
- Easy access to reliable information and social support services may impact knowledge and ability to access appropriate care.
- For people with limited English proficiency, there may not be services or materials available in their spoken language.
- Digital literacy challenges and unreliable internet access can create barriers in a health system that increasingly employs digital communication.
- Some patients may be skeptical of data security.
- Due to underrepresentation in clinical trials and health research, marginalized groups may not be as well represented in the medical information provided.

Strong patient-provider communication has been tied to improved patient experience, decreased emotional stress, improved treatment adherence and compliance, improved health outcomes, and increased caregiver satisfaction and decreased burnout[2].

Potential Policy Solutions

There are many routes that interested stakeholders can take to improve the healthcare information landscape on behalf of patients.

Hospitals, health systems, and practices can help by:

- Creating educational materials using an ongoing, iterative patient-engagement process with the community they intend to serve.
- Implementing policies to ensure all patients are made aware of relevant clinical trials with tools such as the NCI's TrialGPT.
- Investing in training for healthcare professionals and staff on communication skills.
- Partnering with trusted community health liaisons/ cultural insiders to improve the community's engagement with the health system.
- Creating information mediums that allow individuals who have varied learning-style preferences to gain important healthcare knowledge.

Policymakers can help by:

- Establishing and promoting a repository of reliable health information sources easily accessible to the public, such as the NCI's Cancer Information Service.
- Supporting policies that require insurance companies to improve transparency in their processes to improve trust and decrease uncertainty.
- Creating a verification system for use on social media platforms to allow users to differentiate between accurate and unverified information.
- Providing funding for comprehensive health literacy campaigns and programs throughout school systems and media outlets.
- Supporting efforts to ensure reliable access to broadband internet and telehealth services.

Health literacy campaigns, such as the Ask Me 3 educational initiative, have shown success in helping patients remember what was communicated during a physician visit and feel as if they knew more about their illness or medical condition after their visit[4].

Studies have shown low health literacy is associated with more hospitalizations, greater use of emergency care, decreased use of preventive services, higher mortality, and higher health care costs[3].

Works Cited:

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