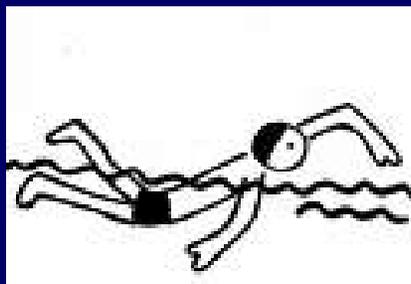


Cancer Survivors – Successfully Swimming or Struggling to Stay Afloat in a Sea of Cancer Information?



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Acknowledgments

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National Cancer Institute

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NCI SEER & HINTS Contracts

Overall Objective

- Based on data from population-based studies identify strategies for supporting the information management efforts of cancer survivors and family members

Part I: Information Needs of Cancer Survivors

Information Needs of Cancer Survivors



ELSEVIER

Patient Education and Counseling 57 (2005) 250–261

Patient Education
and Counseling

www.elsevier.com/locate/pateducou

Review

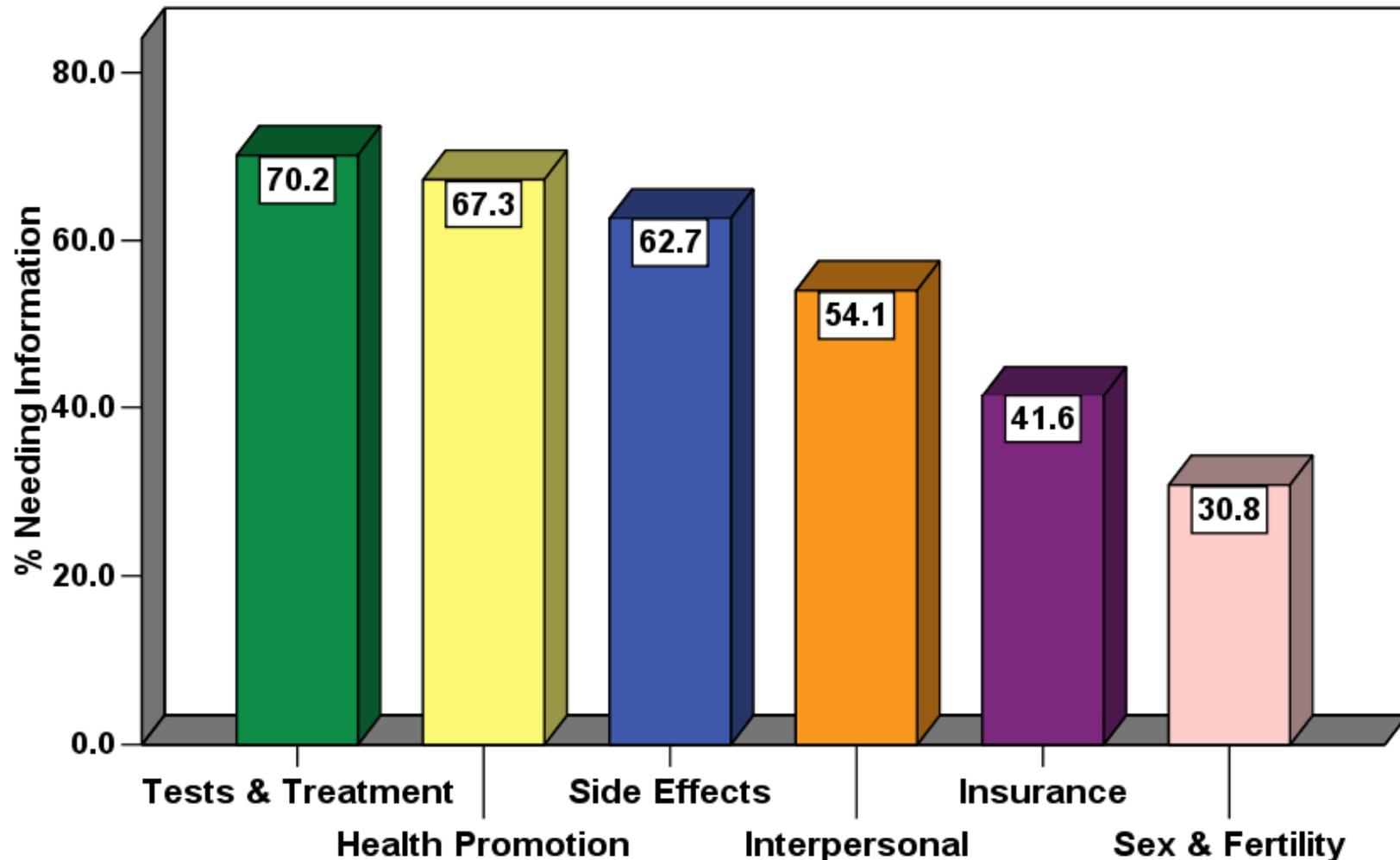
Information needs and sources of information among cancer patients:
a systematic review of research (1980–2003)

Only 9/92 (10%) studies assessed the current needs of post-treatment cancer survivors

Abstract

Understanding what cancer patients need to know and from whom they receive information during the course of care is essential to ensuring quality care. We reviewed 112 articles published from 1980 to 2003 and developed a typology summarizing cancer patients' information needs and the sources from which they receive information. The majority of articles focused on information needs and sources

Information Needs of Survivors 2 - 5 Years Post Dx: SEER Data (N = 1,033)

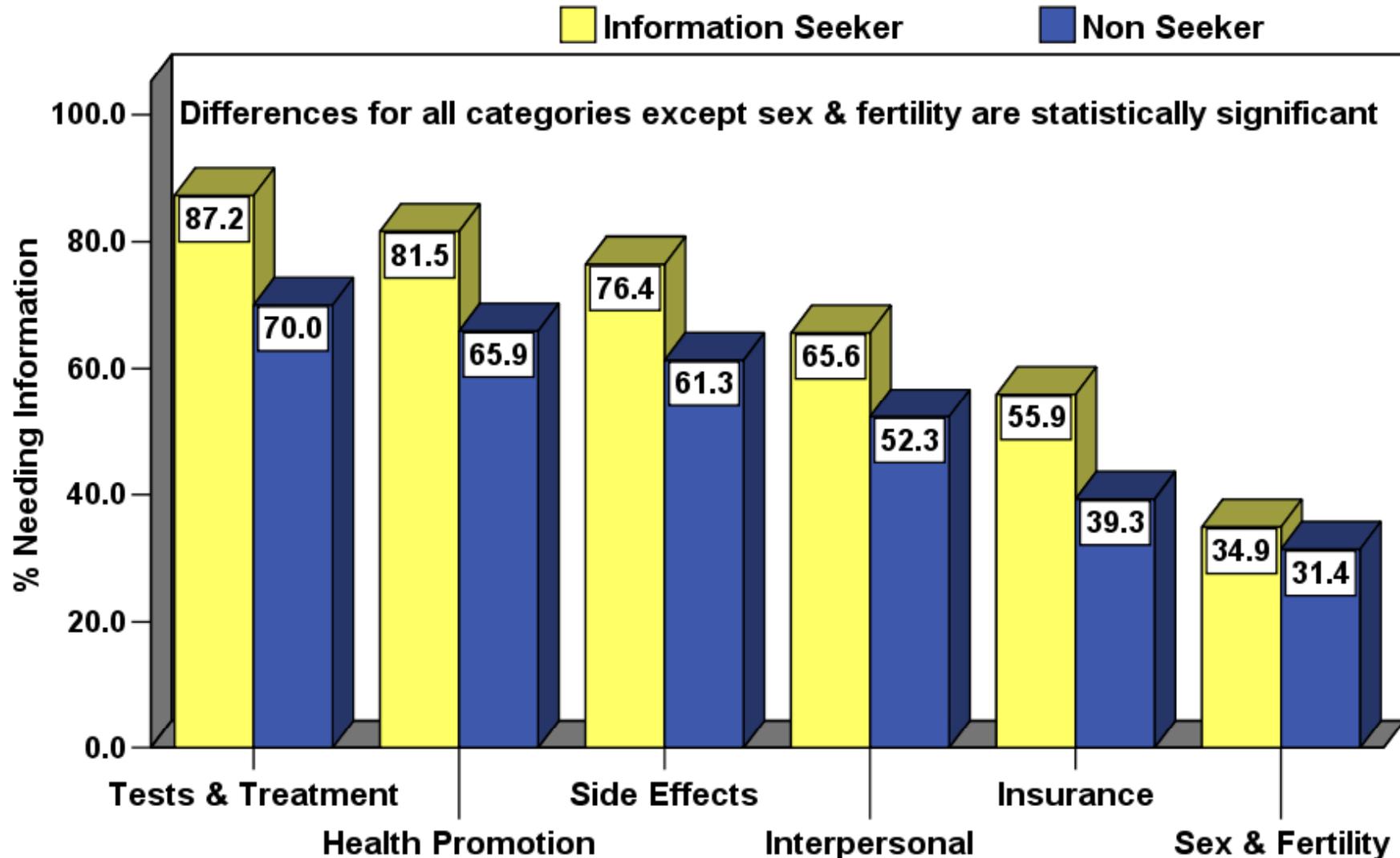


(Beckjord, Arora, Hesse, McLaughlin, Oakley-Girvan, Hamilton – manuscript in preparation)

Information Seeking

- A sub sample (N = 702) of survivors were asked if they had searched for cancer-related information in the past 12 months
- Only **28%** (195/702) had actively engaged in information seeking in the past 12 months

Information Needs by Information Seeking Status (N = 702)

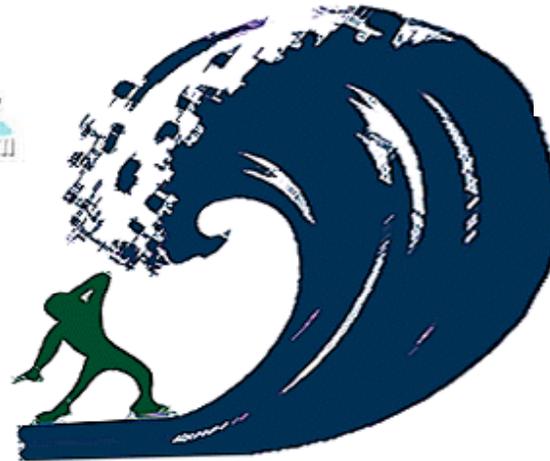


Part II: Information Management Approaches of Cancer Survivors



Dealing with a “Tsunami” of Information?

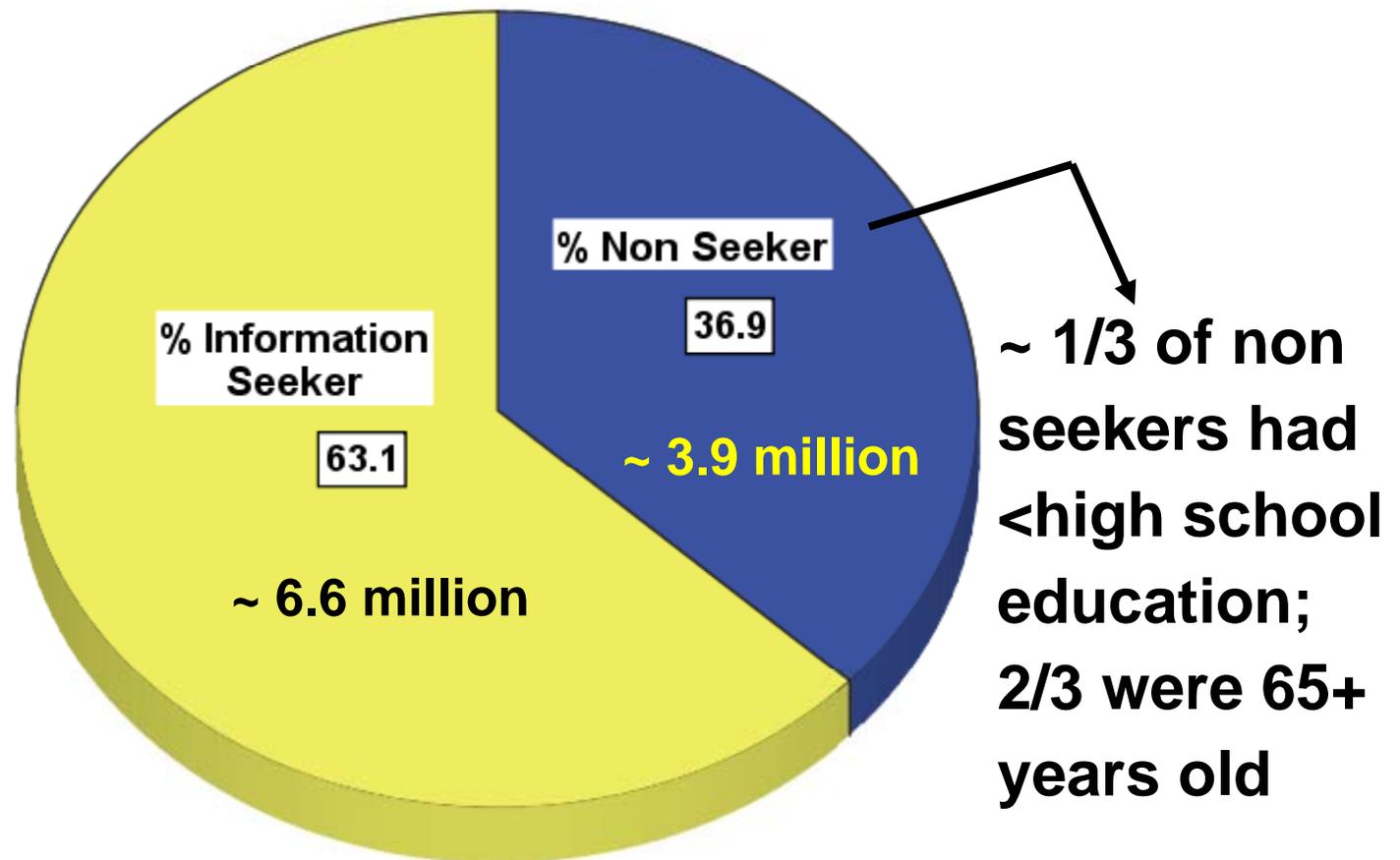
Focus: Role of Health Care Providers and the Internet



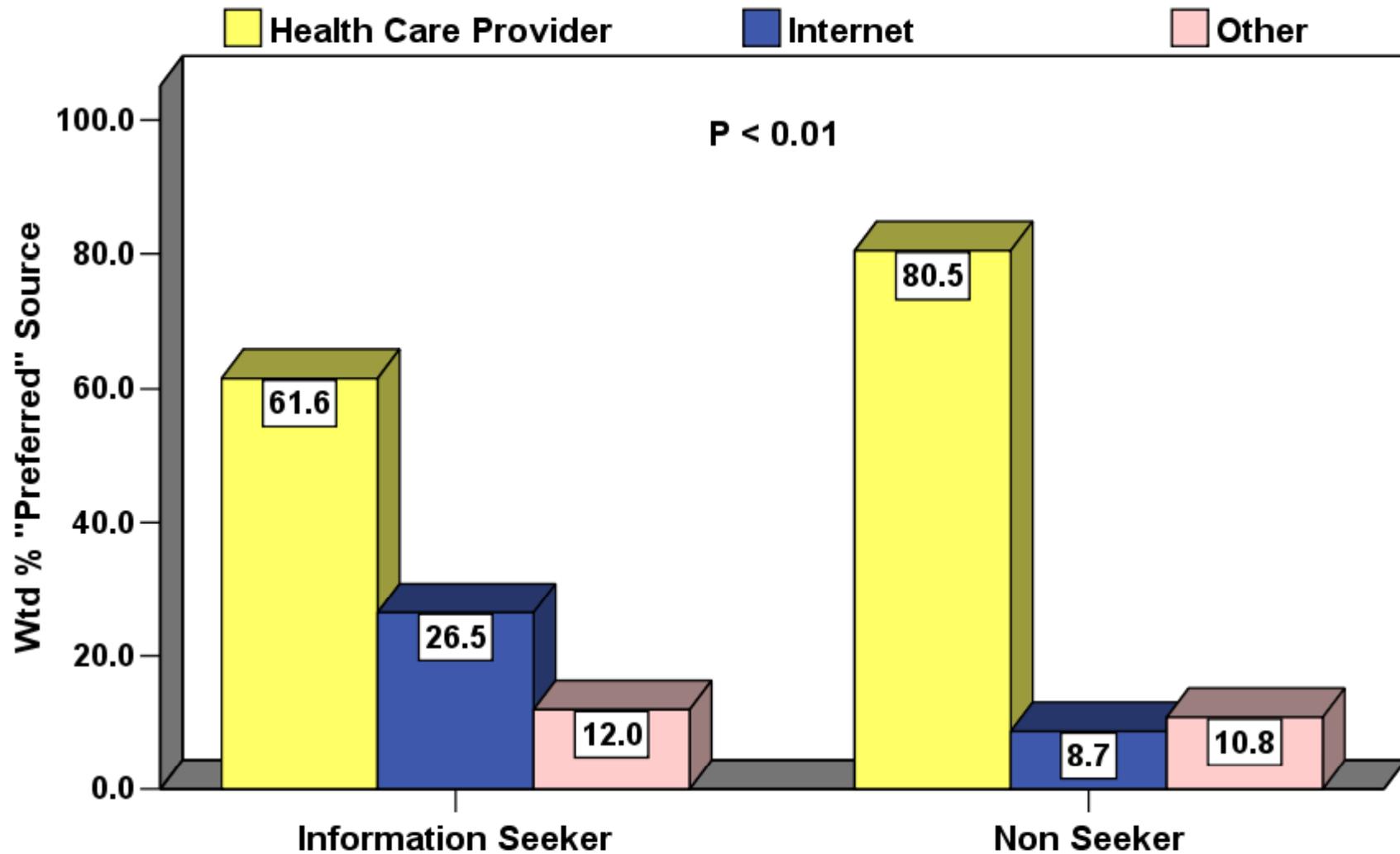
Data Source

- Nationally representative data from the 2005 Health Information National Trends Survey (HINTS): N = 5,586
 - **873 cancer survivors**
 - 3397 family history of cancer
 - 1291 no cancer history
- Survivors grouped by years since dx
 - ≤ 1 year, 1+ to 5, 5+ to 10, 10+ years

% Ever Personally Searched for Cancer Information

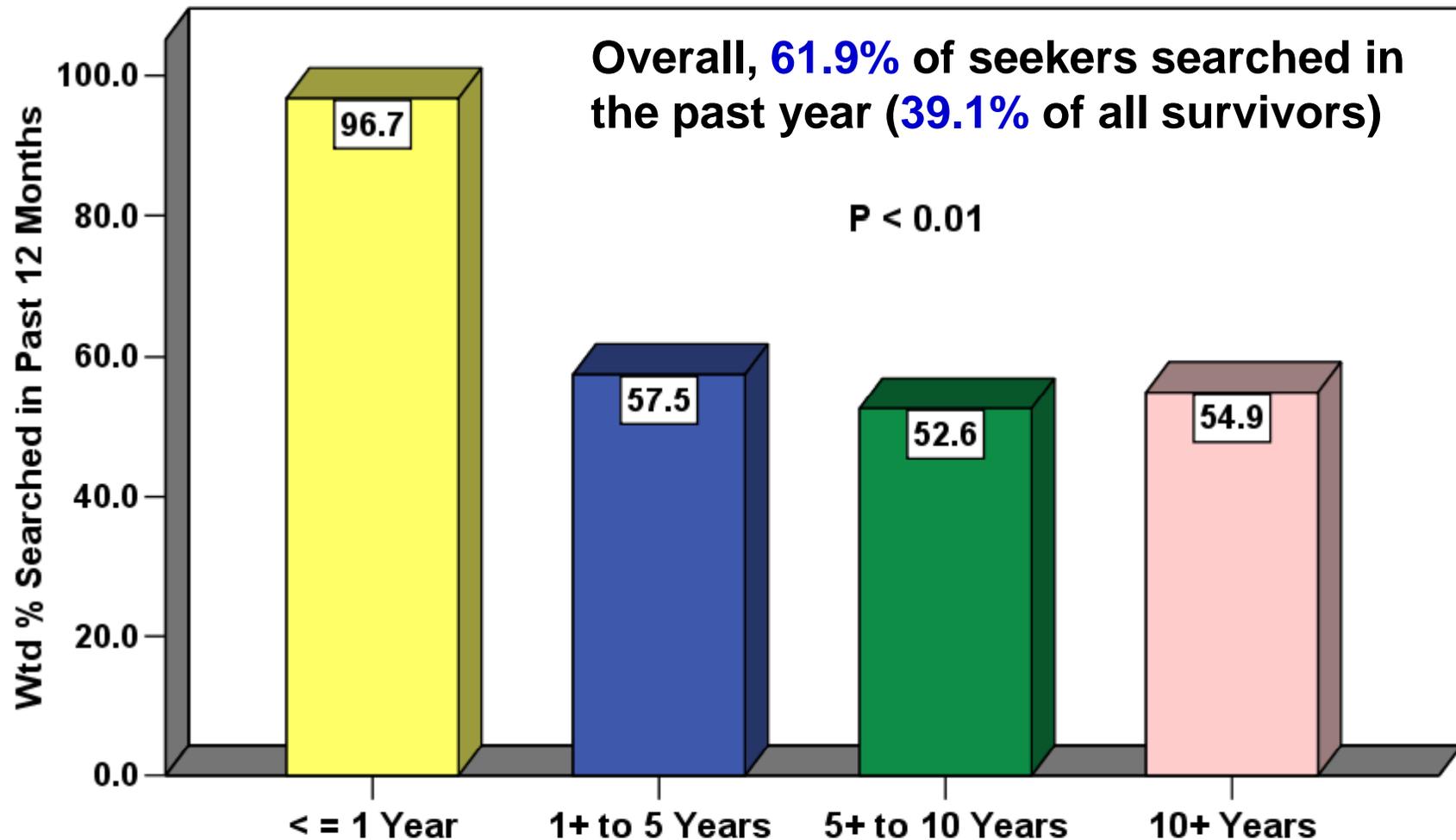


“Preferred” Source of Information by Information Seeking Status



Information Seekers

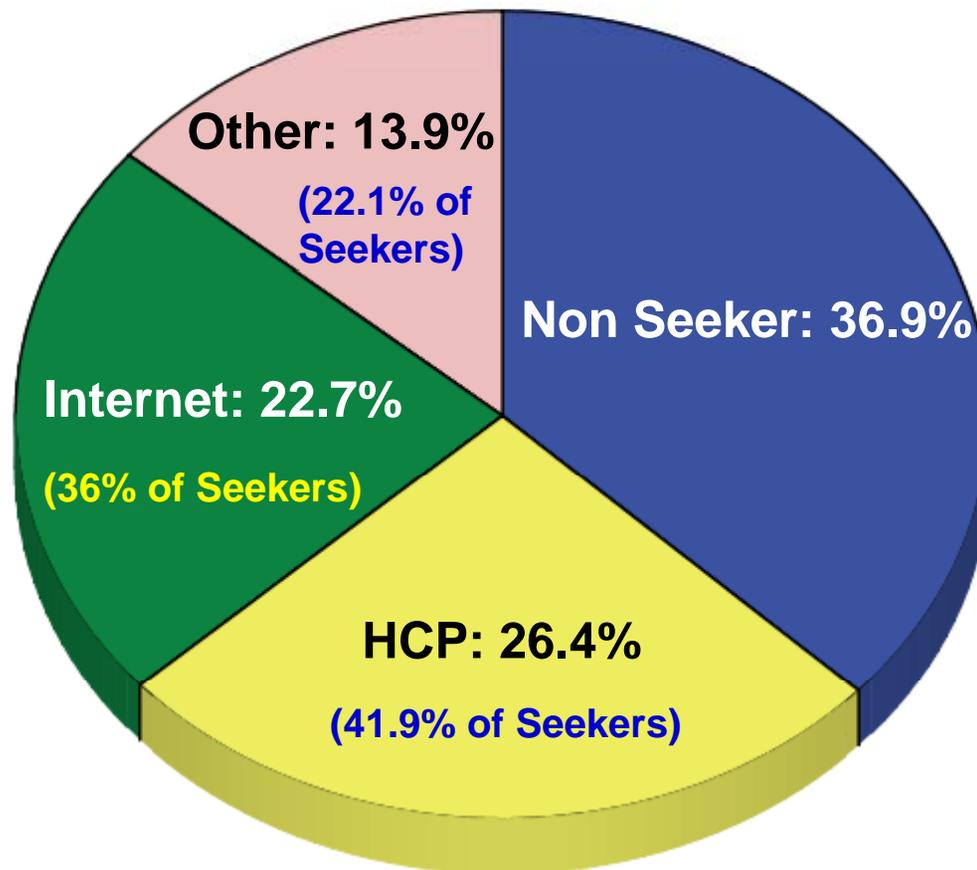
Information Seeking in the Past Year by Time Since Diagnosis



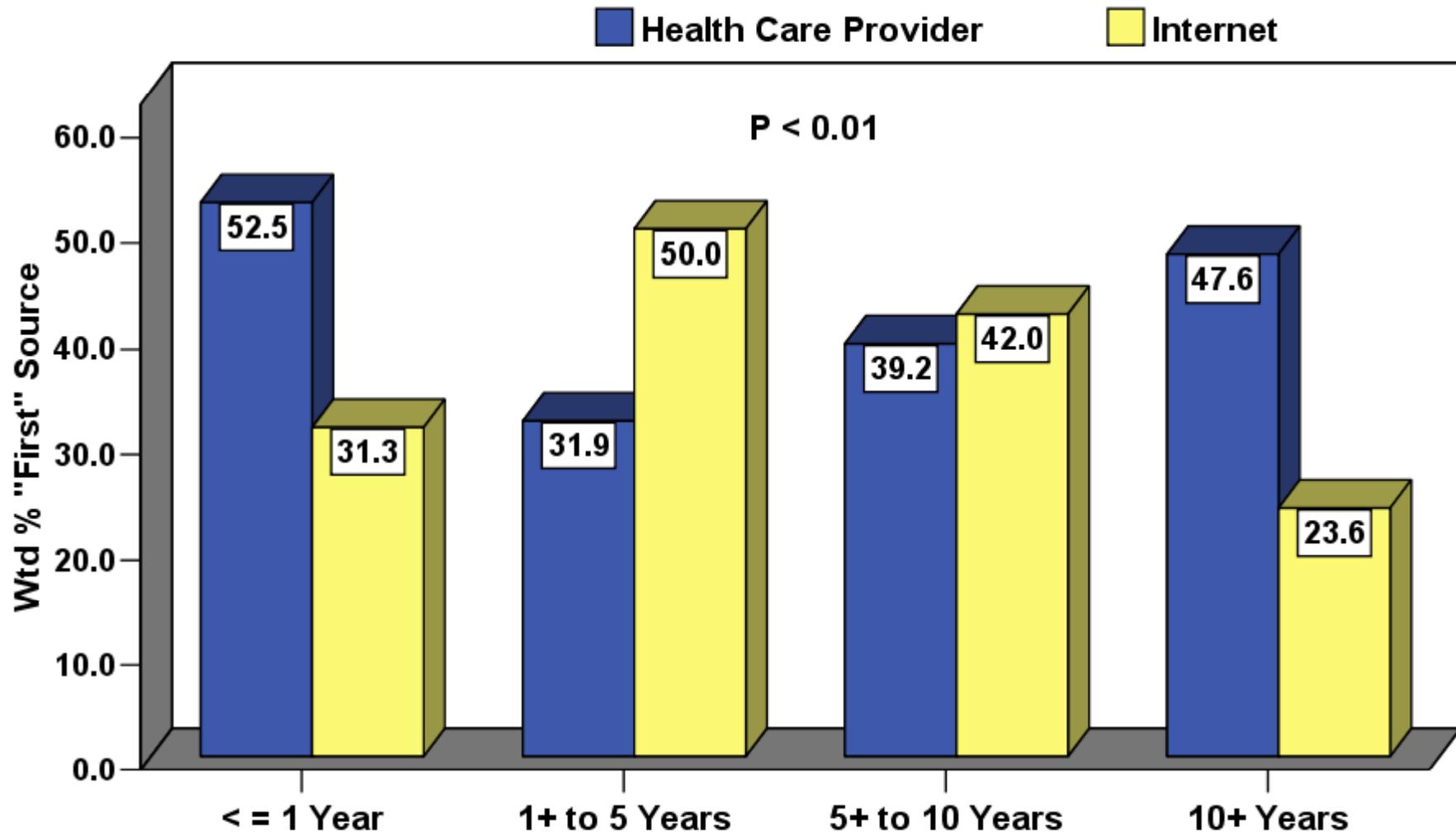
Trust in HCP and the Internet

- **70.9%** of seekers had “**a lot**” of trust in HCPs as a source of information
- **23.6%** had “**a lot**” of trust in the Internet as a source of information
- Trust in HCPs and the Internet **did not** vary by time since diagnosis

“First” Source of Cancer Information



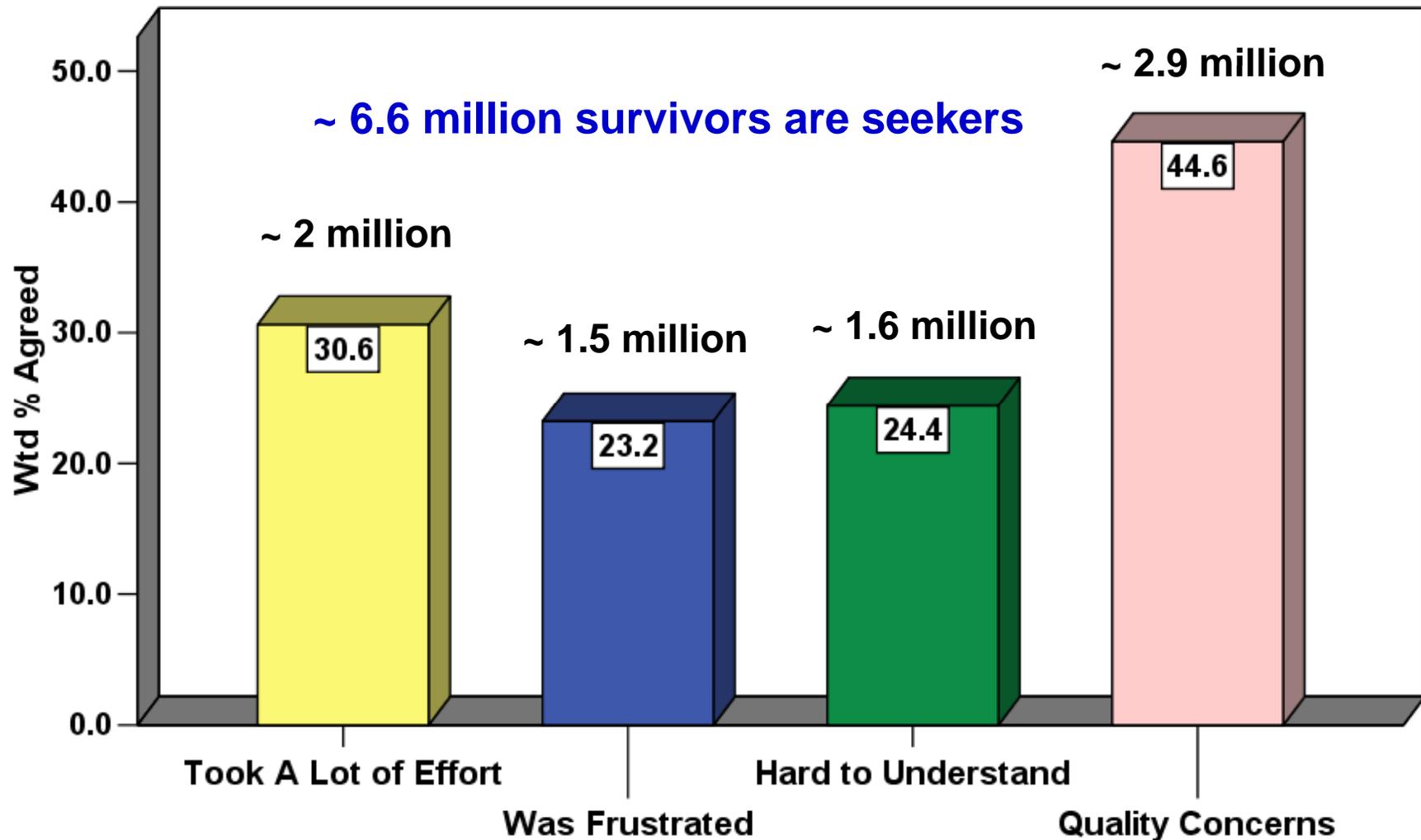
Use of HCP and the Internet by Time Since Diagnosis



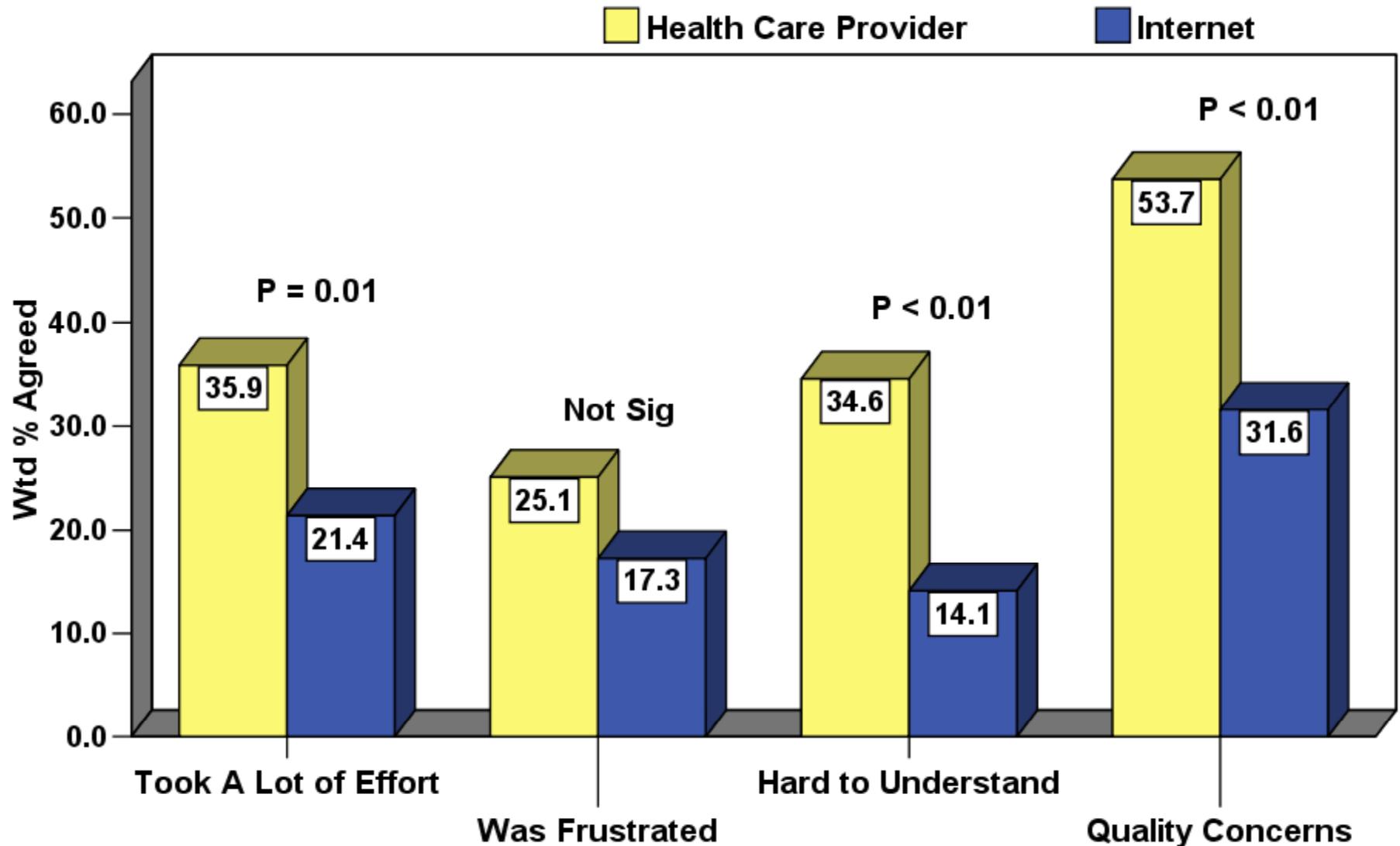
Information Seeking Experience

- Based on the last time they searched, respondents rated four items on a strongly agree/strongly disagree scale
 - **It took a lot of effort to get the information**
 - **You felt frustrated during your search**
 - **The information was too hard to understand**
 - **You were concerned about the quality of the information**

Information Seeking Experience



Information Seeking Experience by “First” Source of Information

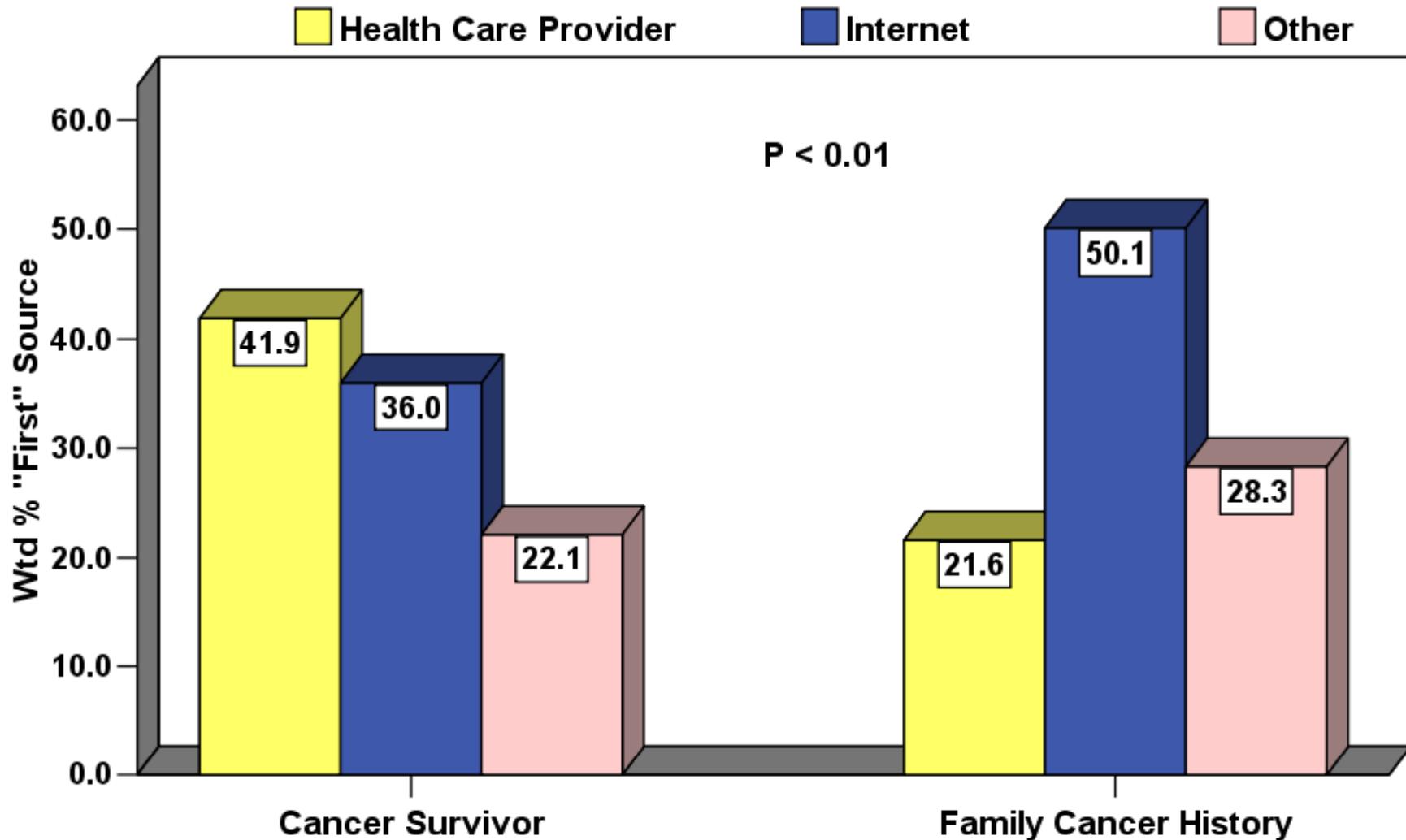


**Part III:
Information Management
Approaches of Individuals with a
Family History of Cancer**

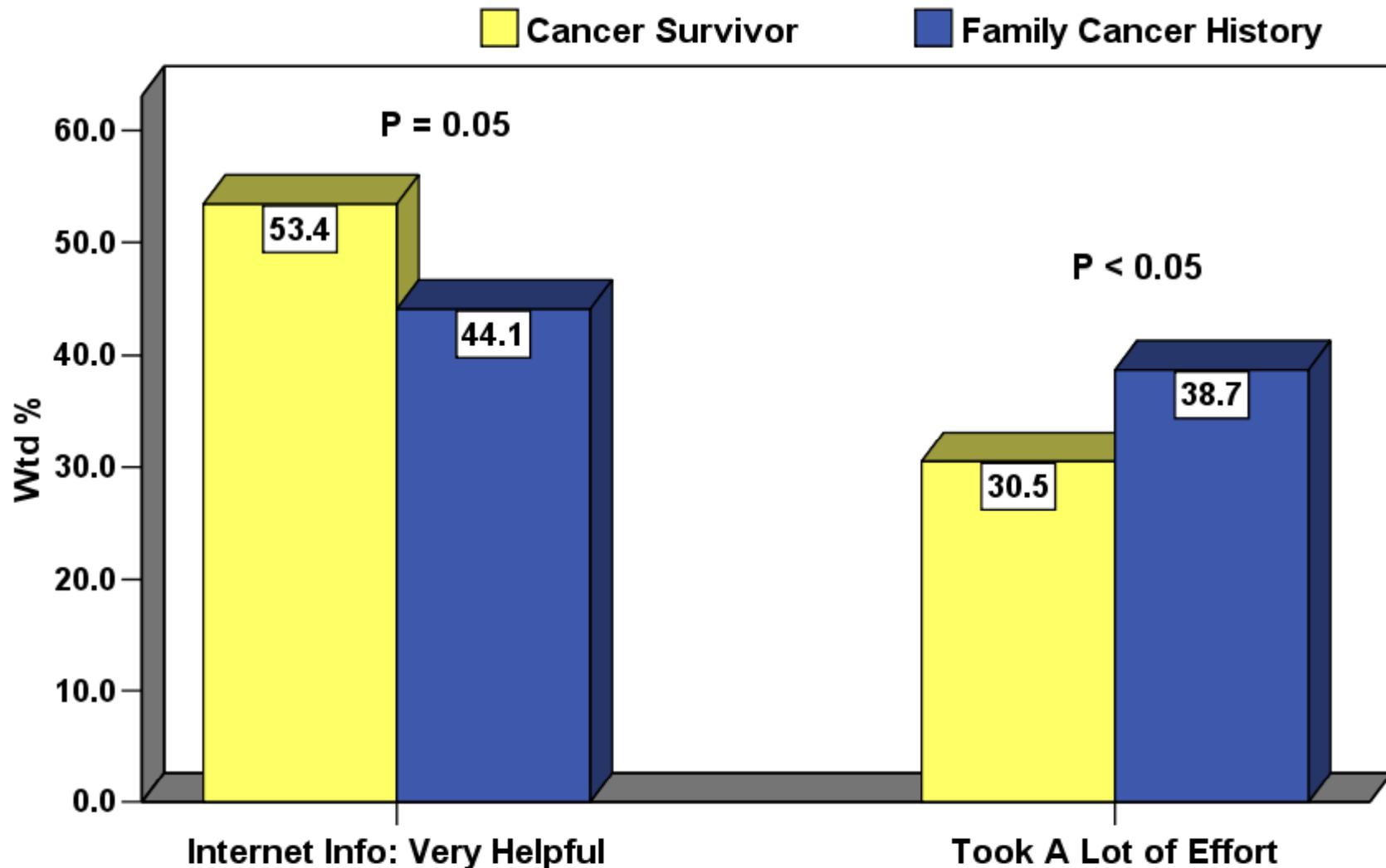
Information Seeking

- **39.7%** searched within the past 12 months (v/s **39.1%** of survivors)
- Levels of trust in HCPs and the Internet were similar for family members and survivors
- Family members had fewer # doctor visits compared to survivors

“First” Source of Information by Survivorship Status



Information Seeking Experiences by Survivorship Status



Summary

- Post-treatment cancer survivors have significant information needs
- Cancer survivors rely on both HCPs & the Internet for cancer information
- A quarter to almost half of cancer survivors seeking information report sub-optimal experiences

Summary

- Survivors who do not actively seek information and individuals with a family cancer history are likely to need increased information support and warrant special attention

Embracing the Future ...

**Health Care Providers & the Internet:
Complementary or Alternative??
Sources of Support**

Embracing the Future ...



<http://cancersurvivorsproject.org/>

Cancer Survivors Project
a community resource for
long term survivors of cancer

Embracing the Future ...

Internet-based support technologies need to be integrated within the health care system resulting in a seamless environment of **unfailing, DEEP** support that cancer survivors may access 24/7



Embracing the Future ...



Embracing the Future ...

