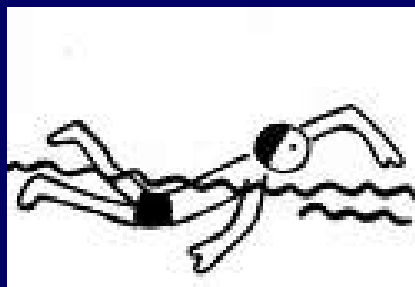


# Cancer Survivors – Successfully Swimming or Struggling to Stay Afloat in a Sea of Cancer Information?



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# Acknowledgments

## Collaborators:

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National Cancer Institute

## Source of Funding:

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

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Patient Education  
and Counseling

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[www.elsevier.com/locate/pateducou](http://www.elsevier.com/locate/pateducou)

Review

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

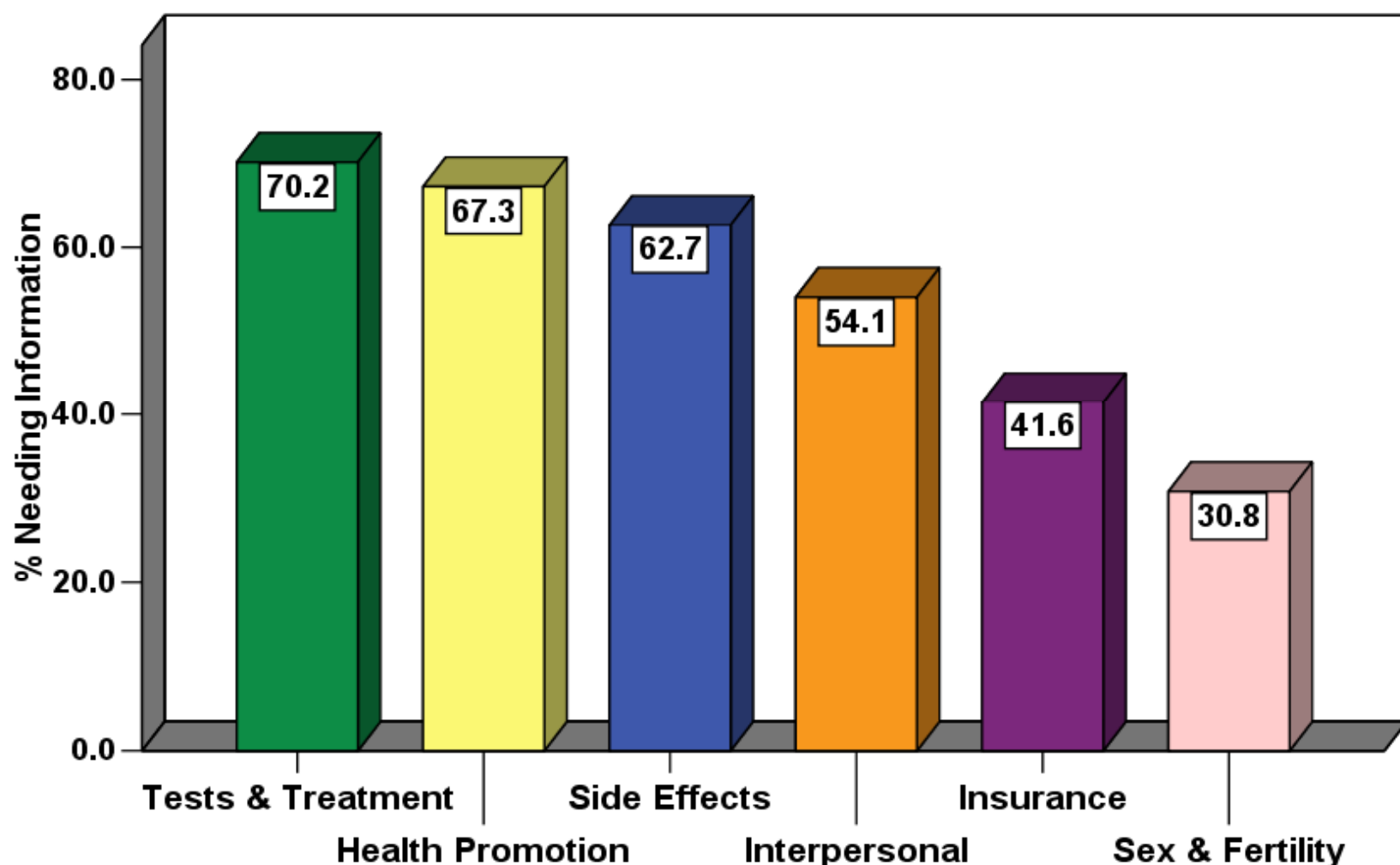
**Only 9/92 (10%) studies assessed the  
current needs of post-treatment cancer  
survivors**

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## 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)

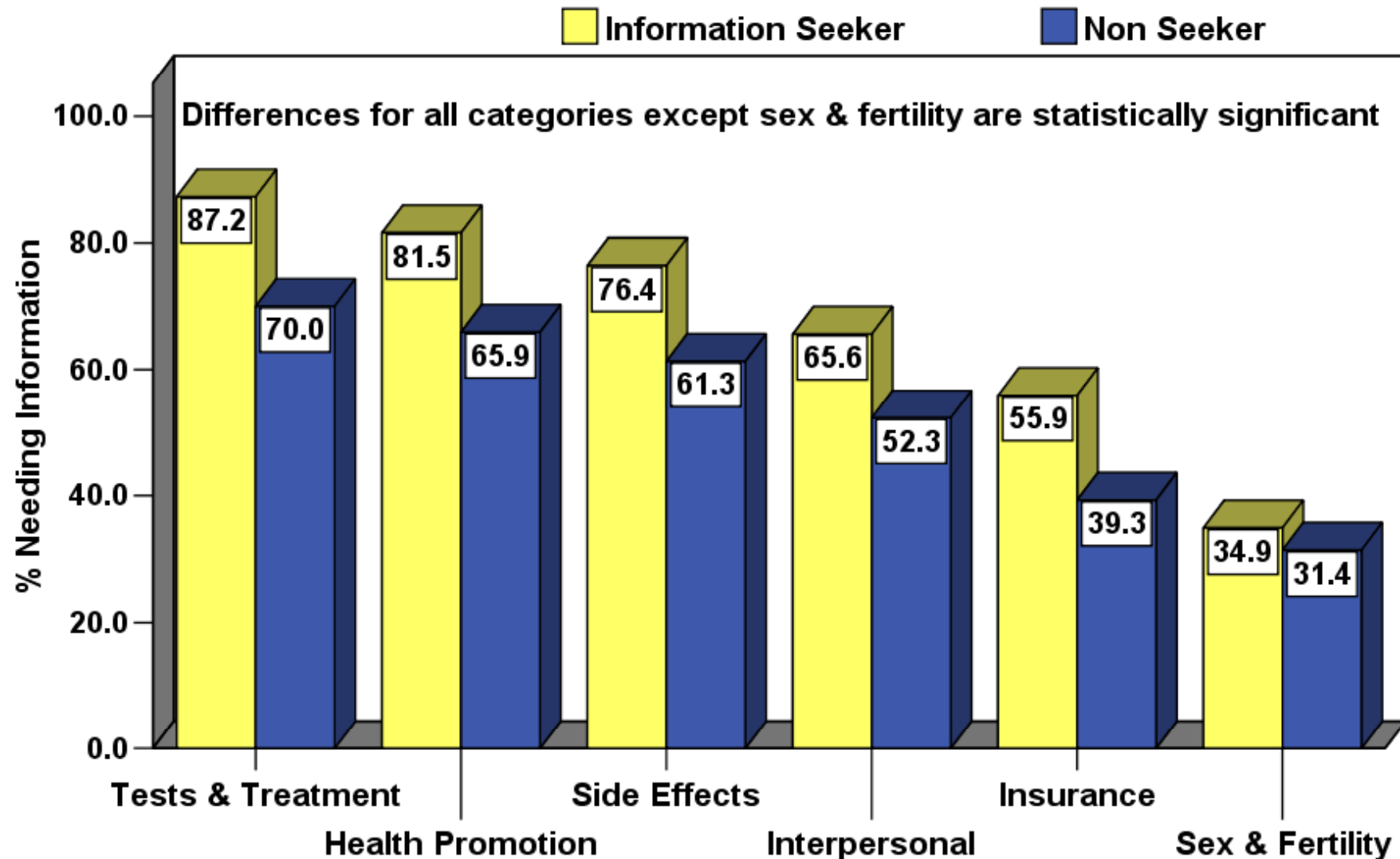


(Beckjord, Arora, Hesse, McLaughlin, Oakley-Girvan, Hamilton – manuscript in preparation)

## 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?

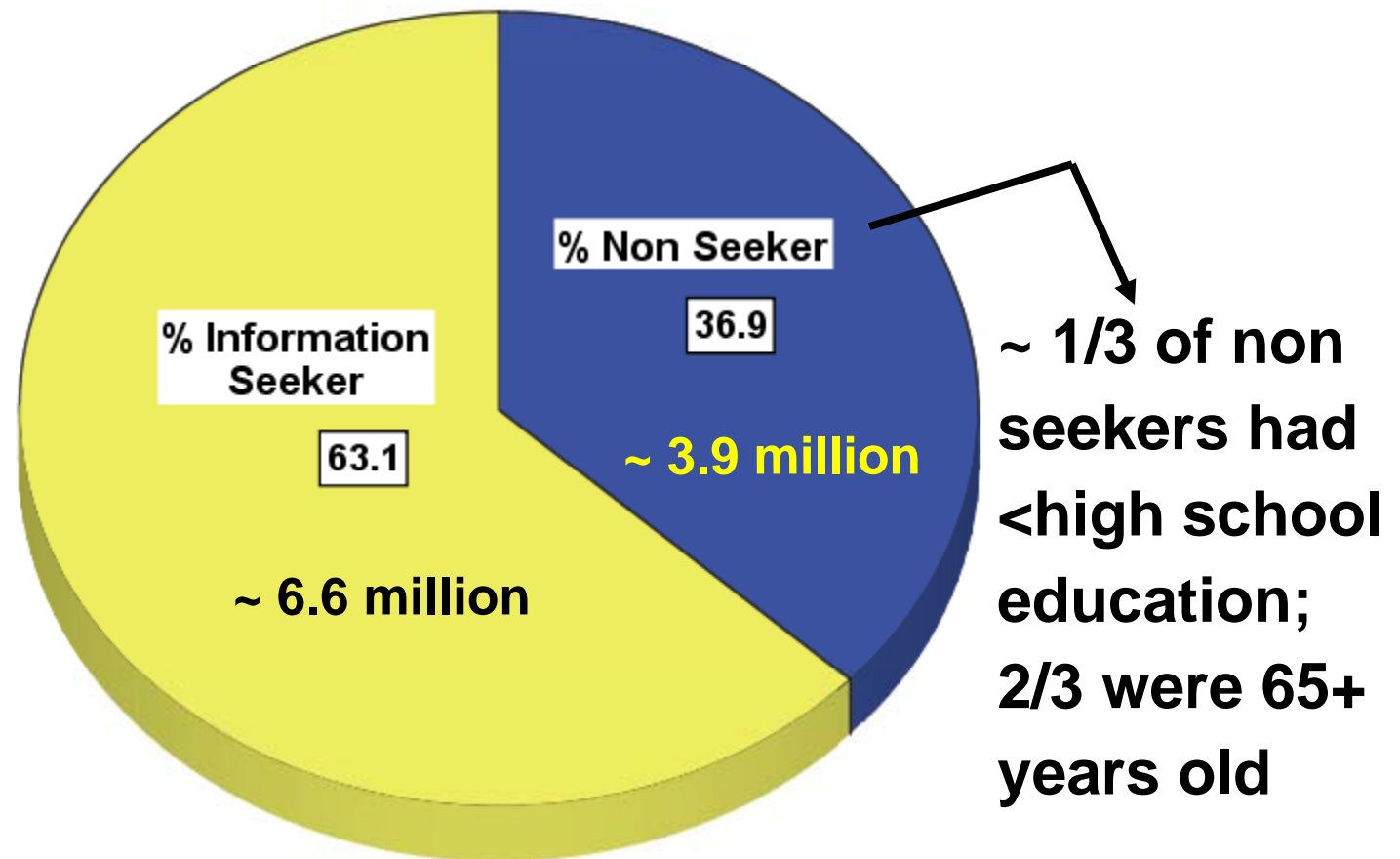
# Focus: Role of Health Care Providers and the Internet



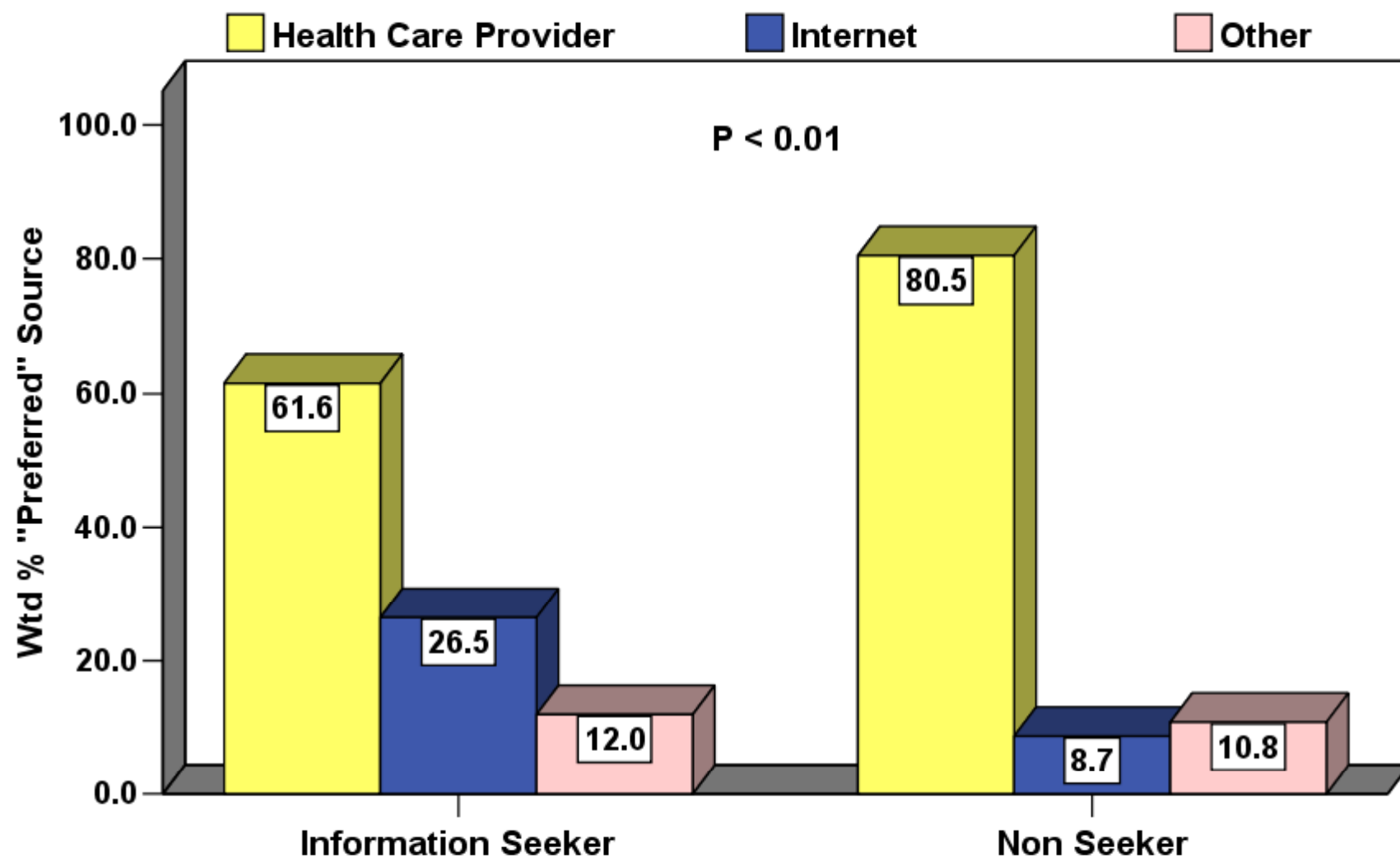
## Data Source

- 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
  - $\leq 1$  year, 1+ to 5, 5+ to 10, 10+ years

# % Ever Personally Searched for Cancer Information

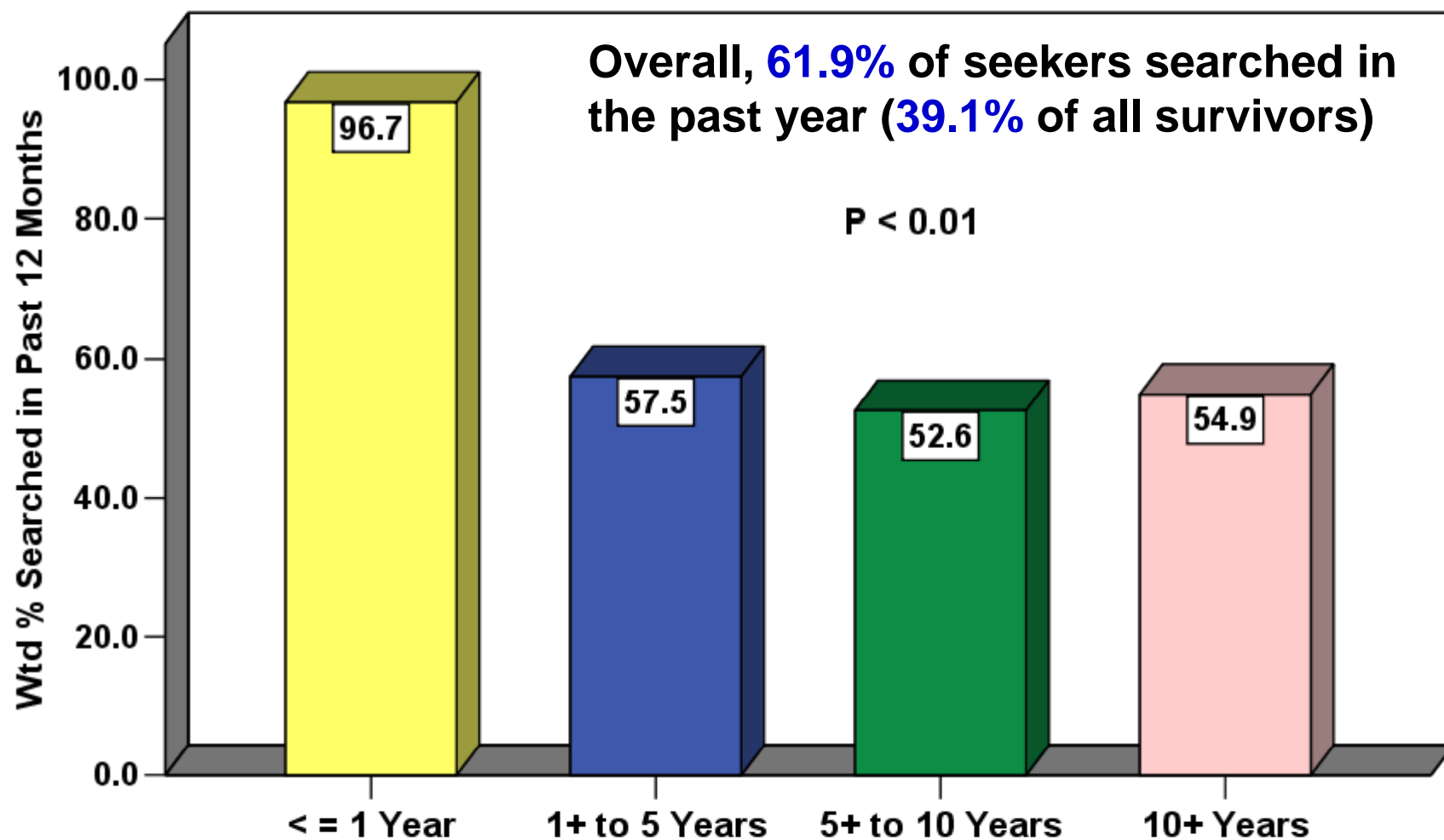


# “Preferred” Source of Information by Information Seeking Status



# Information Seekers

# Information Seeking in the Past Year by Time Since Diagnosis

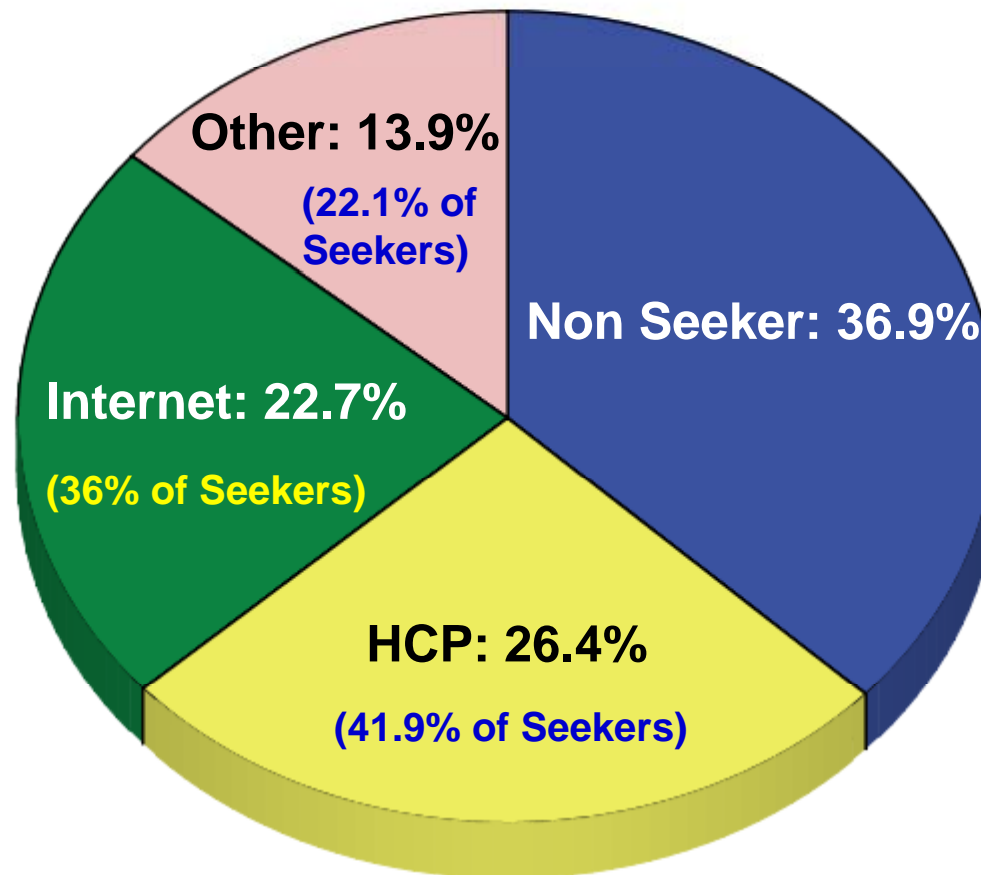


## Trust in HCP and the Internet

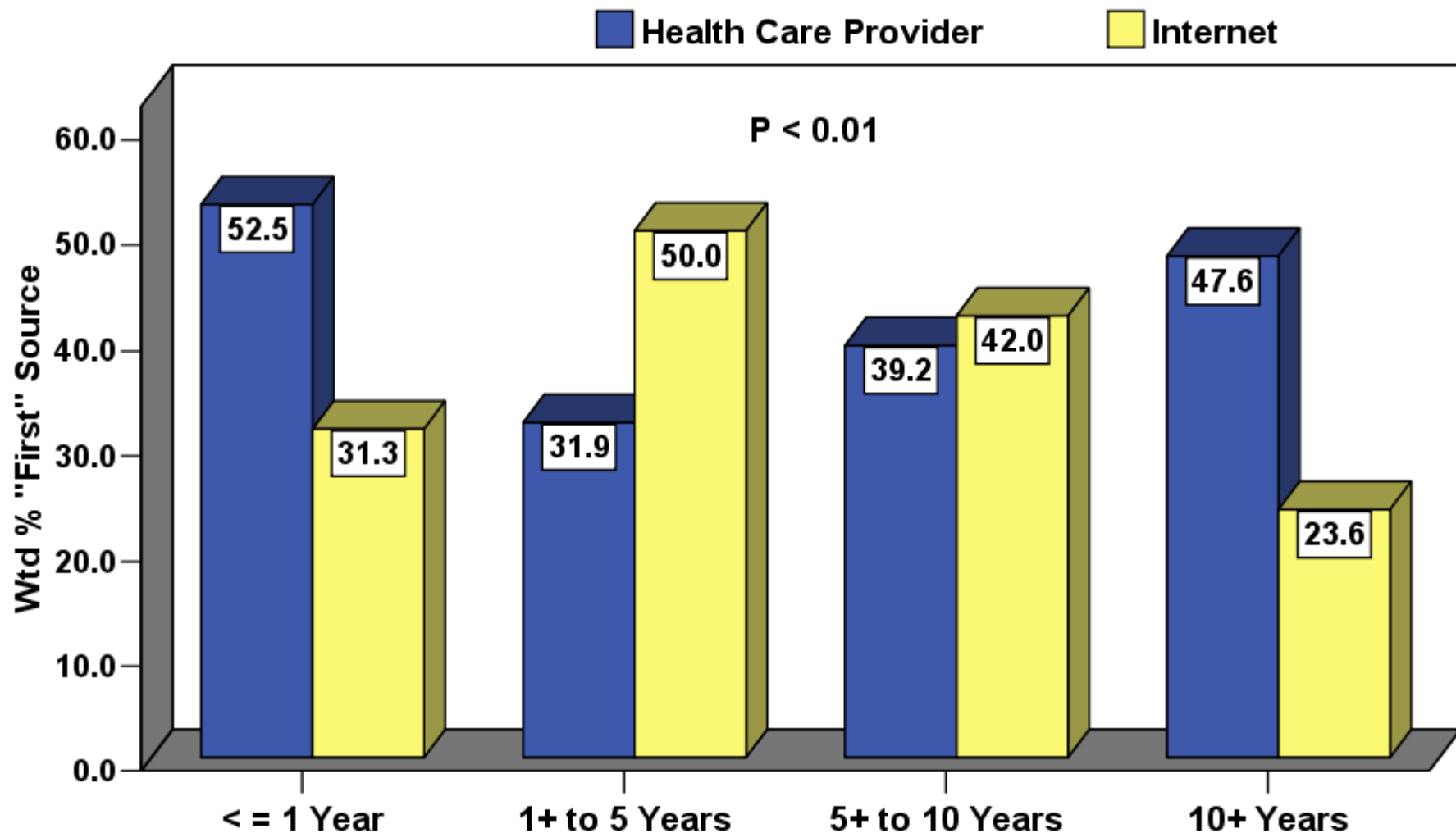
- **70.9%** of seekers had “**a lot**” of trust in HCPs as a source of information
- **23.6%** had “**a lot**” of trust in the Internet as a source of information
- Trust in HCPs and the Internet **did not** vary by time since diagnosis



# “First” Source of Cancer Information



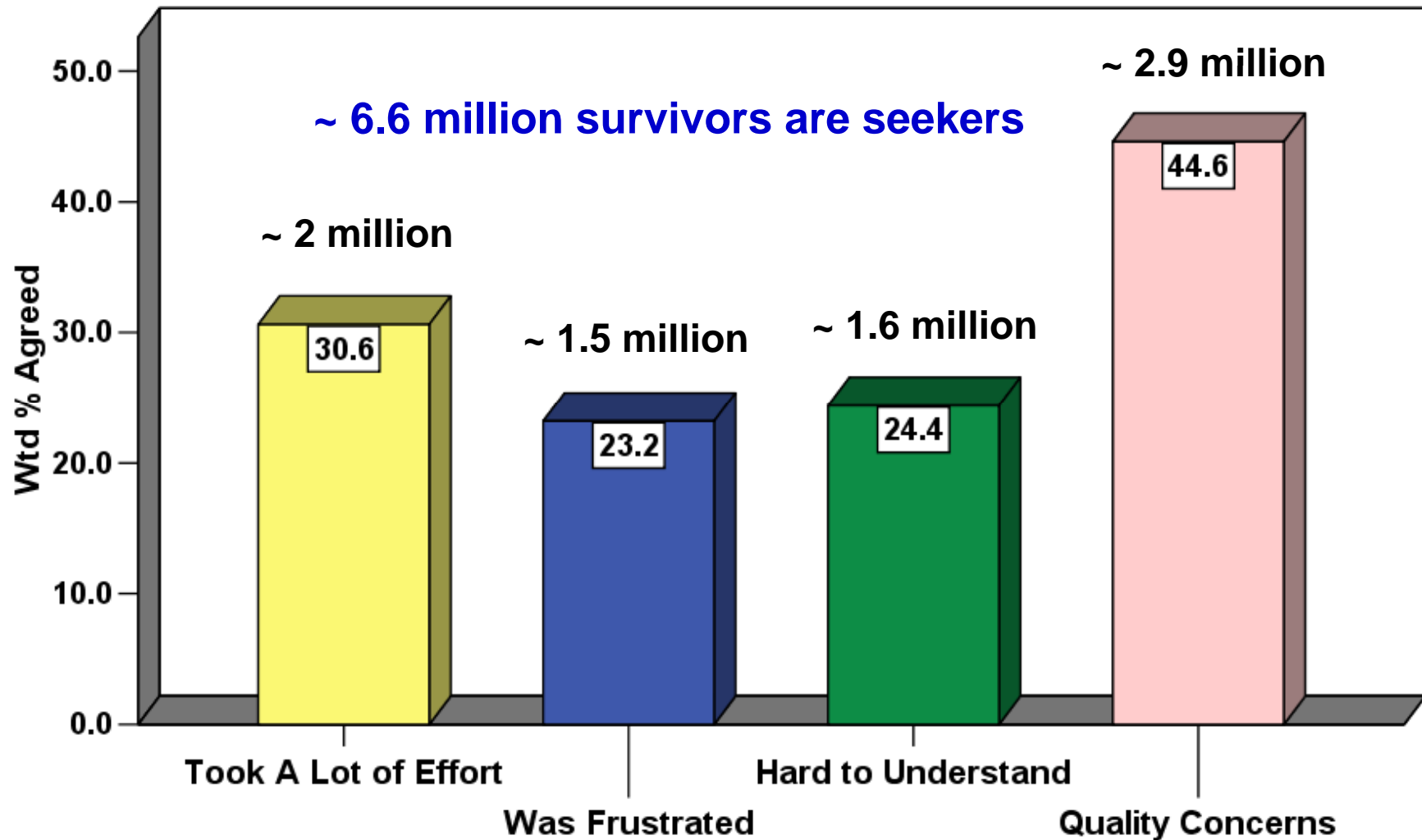
# Use of HCP and the Internet by Time Since Diagnosis



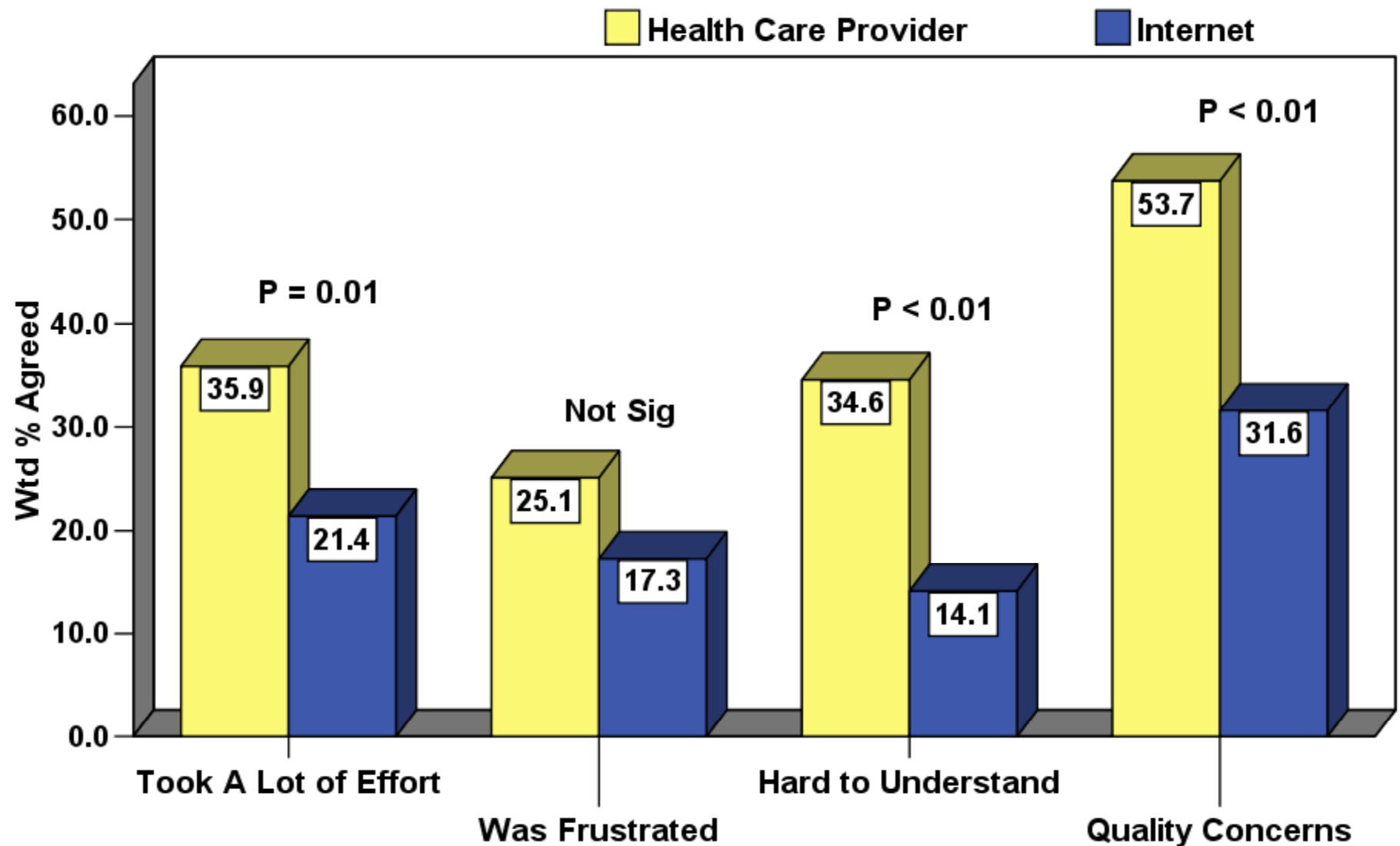
## Information Seeking Experience

- 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

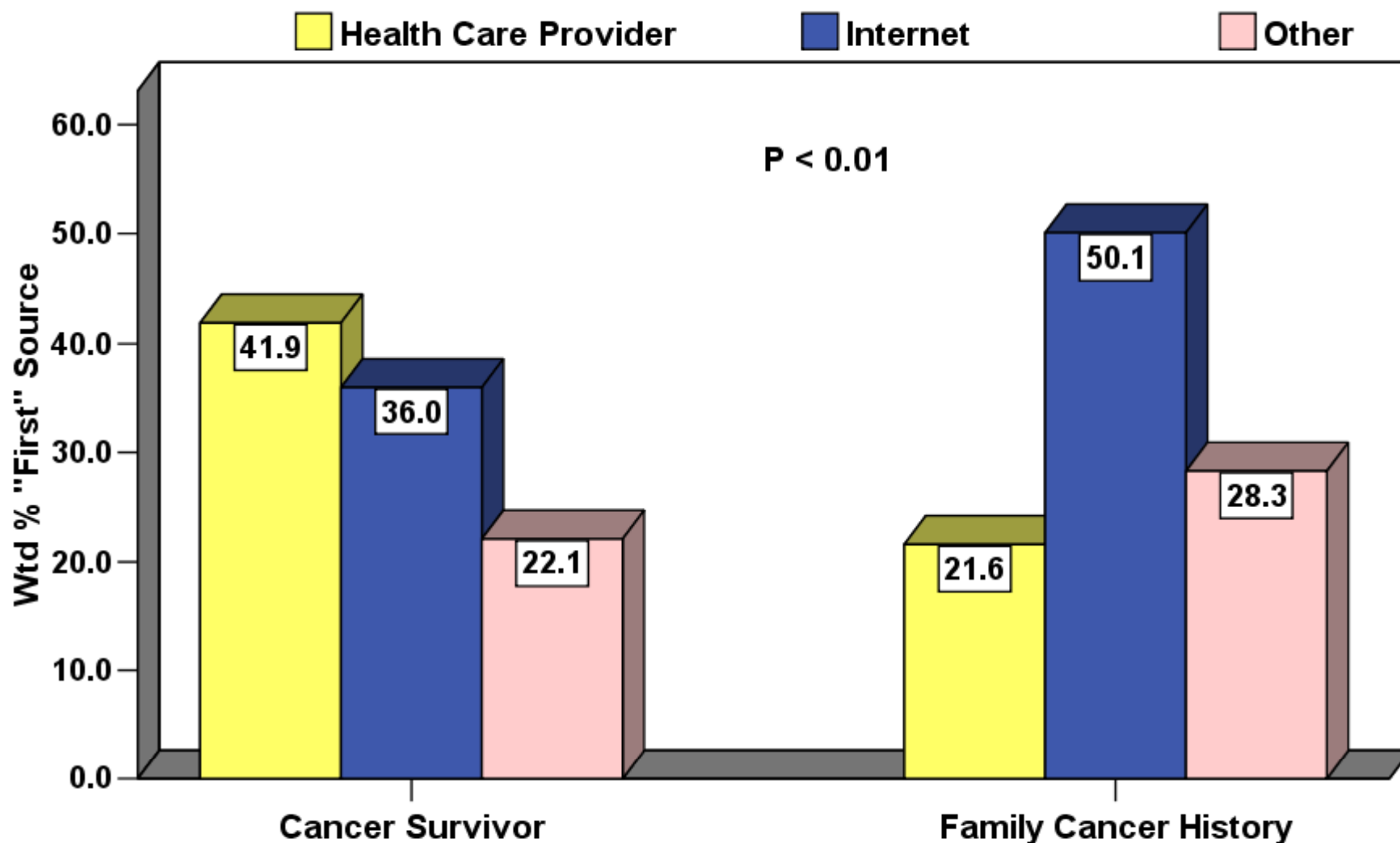


# **Part III: Information Management Approaches of Individuals with a Family History of Cancer**

## Information Seeking

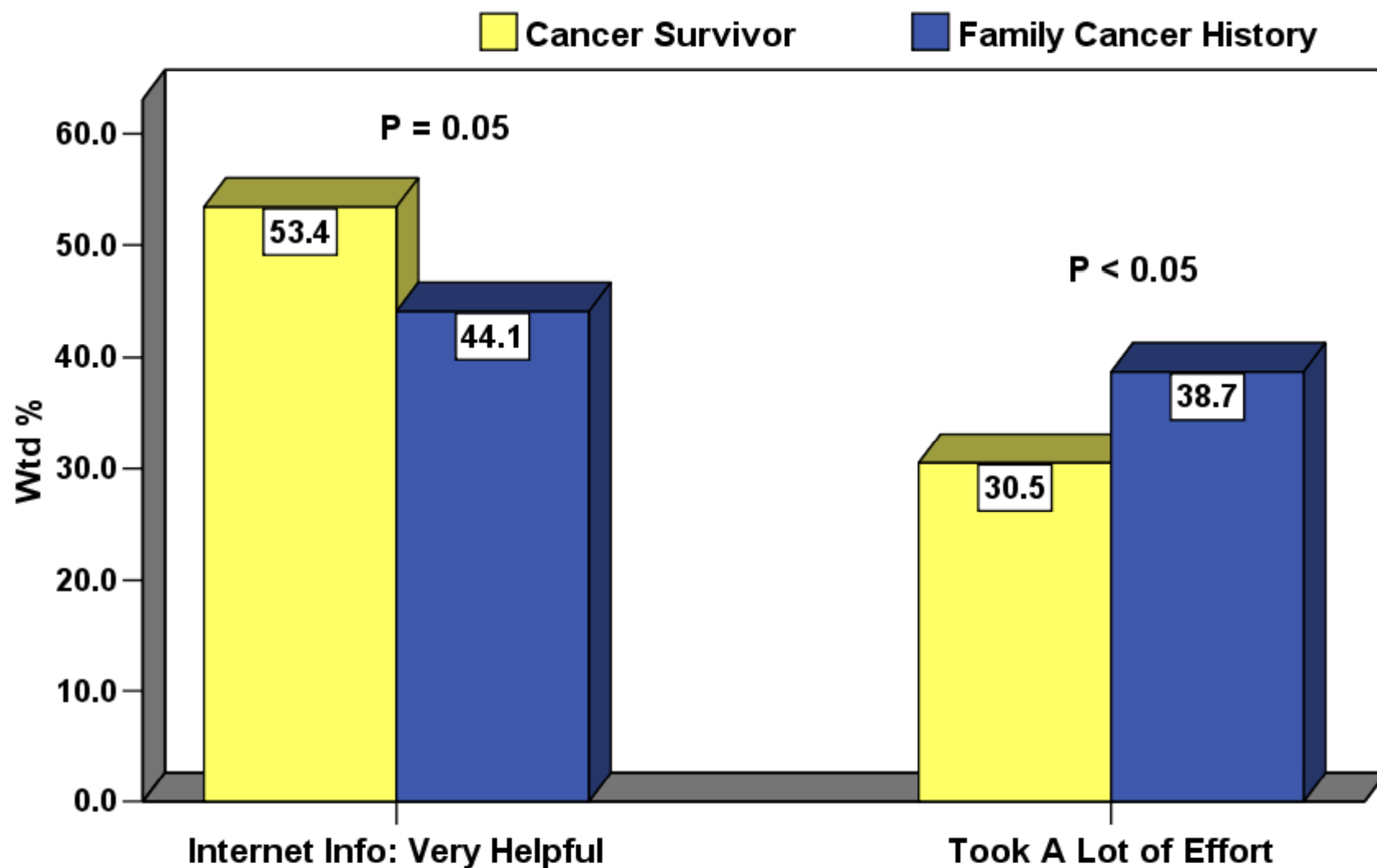
- **39.7%** searched within the past 12 months (v/s **39.1%** of survivors)
- Levels of trust in HCPs and the Internet were similar for family members and survivors
- Family members had fewer # doctor visits compared to survivors

# “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 ...

