Harnessing the potential of the Internet: Developing a web-based self-management program for adolescents with arthritis

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SickKids

Juvenile Idiopathic Arthritis

- Common pediatric rheumatic condition
- Impact all aspects of HRQL
- Disease management can be complex
- Adolescents expected to assume greater role in managing their disease
- Adherence is less than optimal
- Better self-management early on could help prevent worsening of the disease and its symptoms

More about the problem…

- The vast majority of adolescents do not receive comprehensive disease education linked with self-management skills due to:
  - difficulty accessing these services (e.g., long-wait times)
  - limited availability of trained professionals especially in rural areas (psychologists)
  - costs (e.g., time, travel) associate with these therapies

  (Barlow & Ellard, 2004)

- Better self-management early on could help prevent worsening of the disease and its symptoms

Self-Management Interventions

- While these therapies have been found to be effective in adults *(ASMP; Warsi 2003)*, evidence for their effectiveness in children is sparse
- Psycho-educational interventions for children:
  - limited in scope (adherence)
  - directed at parents rather then adolescents
  - delivered in individual or group sessions in specialty clinics by highly trained personnel
  - not suitable for wide-spread distribution in community and/or home-based settings

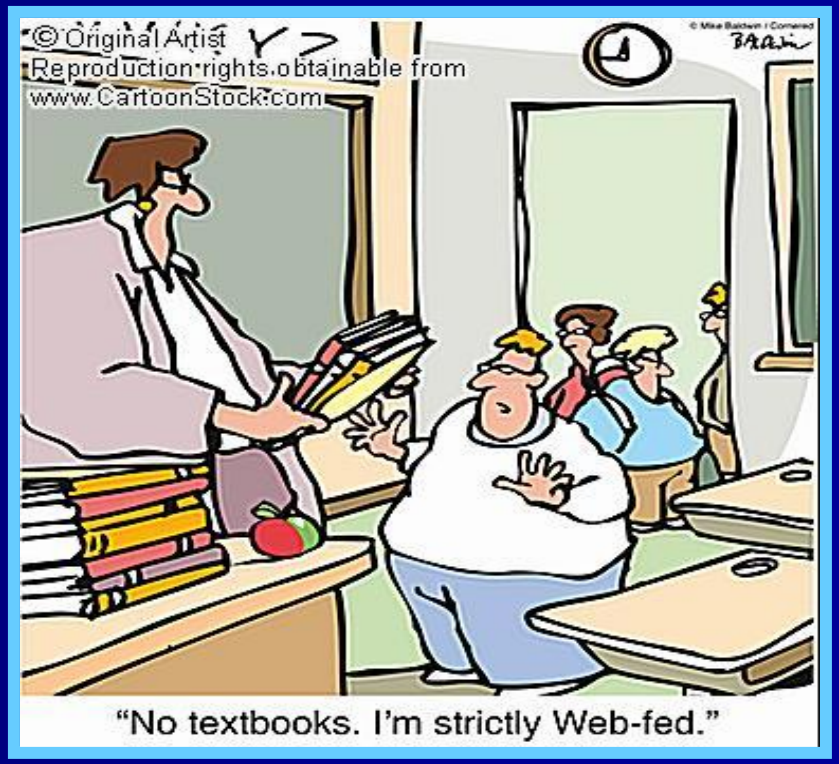
(Barlow et al., 1999; Barlow & Ellard, 2004)

e-health Technologies

- Innovative approach to improving clinical outcomes
- Interactive applications (i.e., Internet, interactive TV and voice response systems, kiosks, PDAs, CD-ROMs, DVDs)
- Supporting and enabling health behavior change and the prevention and management of chronic disease

Why use the Internet?

- Internet is the top source of health Information
  (Gray et al., 2005)
- Can improve:
  - availability
  - accessibility
  - acceptability



"No textbooks. I'm strictly Web-fed."

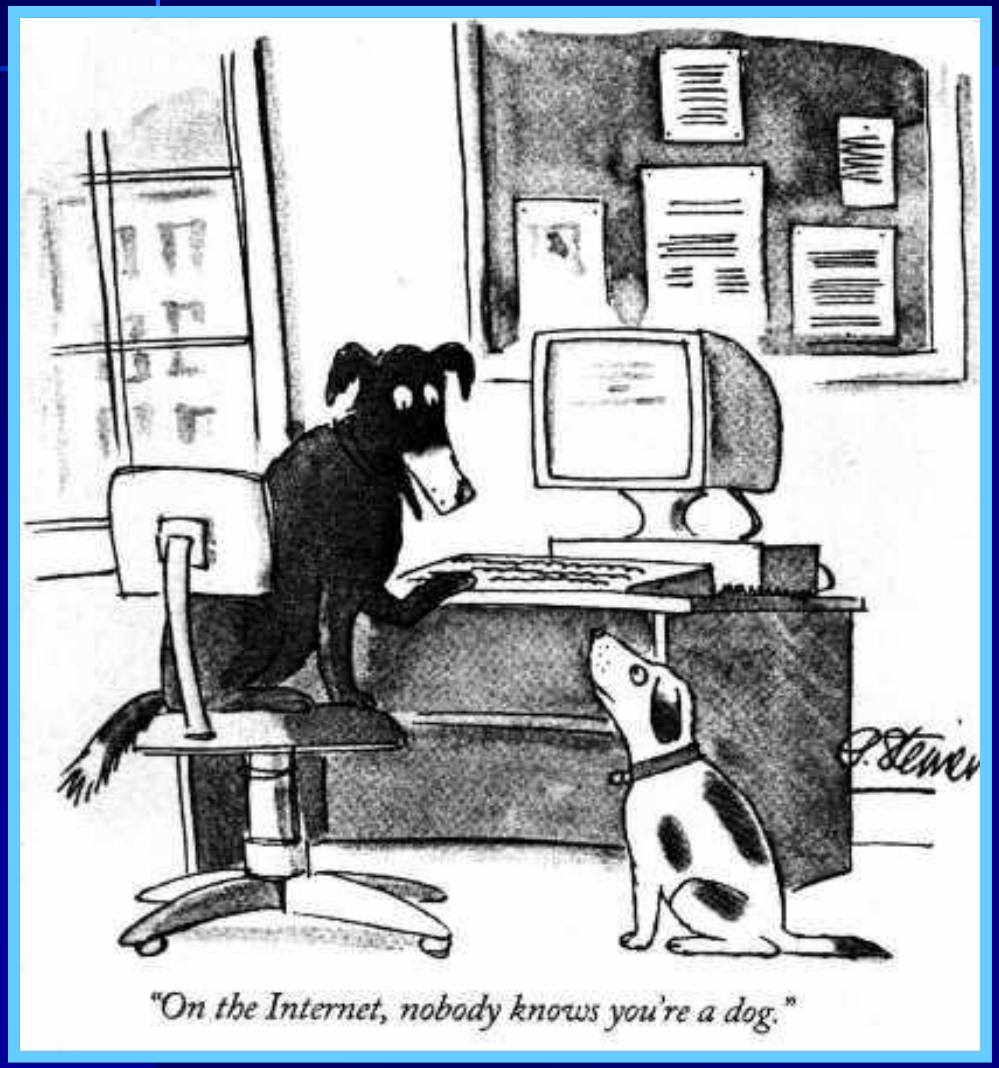
Interactive Health Communication Applications

- Computer-based (1° Internet) interventions
- Health information plus (at least one of):
  - social support
  - decision making support
  - behavioural change support
- Augment information and support provided by health care professionals *(Murray et al., 2007)*

Potential of Internet Interventions

- Beginning evidence of their effectiveness
- Large positive effects in terms of:
  - improved knowledge
  - feel more socially supported
- May have improved behavioural and clinical outcomes
- May improve self-efficacy (a person's belief in their capacity to carry out a specific action)
- Unable to determine effect on emotional and economic outcomes *(Murray et al., 2007)*

Advantages of Internet Programs



- Private access to information at any time
- Wide range of interactive self-management modules enables tailoring to needs
- A secure server can deliver, customize and record homework sessions and provide adolescents with opportunity to communicate with members of the health care team and peers
- Highly appealing mode of communication

Internet based Interventions in Children

- Few self-administered, multimedia programs for children and adolescents with chronic illnesses have been developed and validated despite their appeal *(Murray et al., 2007; Wetland et al., 2004)*
- There is early evidence that computer-based, self-administered treatments are efficacious for children with asthma *(Shegog et al., 2001; Krishna et al., 2003; Joseph et al 2007)*, diabetes (*Brown et al., 1997, Gerber et al., 2007)*, headaches *(Hicks et al., 2006, Connelly et al., 2006*), cancer *(Beale et al., 2007)*, and eating disorders *(Heinicke et al., 2007)*

Teens Taking Charge Managing Arthritis: On-line

Co-Investigators

McGrath, Hodnett, Feldman,
Duffy, Huber, Tucker, Yeung, Hetherington

Teens Taking Charge: Managing Arthritis On-line

- Phase 1: Needs assessment (Asking the experts)
- Phase 2: Development and usability testing
- Phase 3: Feasibility testing (pilot RCT)
- Phase 4: Multi-centred RCT

Self-management needs of adolescents with arthritis: Asking the experts

Letting Go: Gaining Control

- **Gaining knowledge and skills to manage the disease**
  - •Knowledge and awareness about the disease
  - •Listening to and challenging care-providers
  - •Communicating with the doctor
  - •Managing pain
  - •Managing emotions
- **Understanding through Social support**

(Stinson et al., 2008)

Phase 2: Site Development and Usability Testing

The Steps

Teens Taking Charge: Managing Arthritis On-line

- Multi-component, multi-media program
  - information
  - self-management skills
  - social support (discussion board, stories of hope, video clips)
- 12 modules for adolescents (12-18 years)
- 2 modules for parents
- Health coach (facilitate achievement of health-related goals, tailoring information)

Content Development Team

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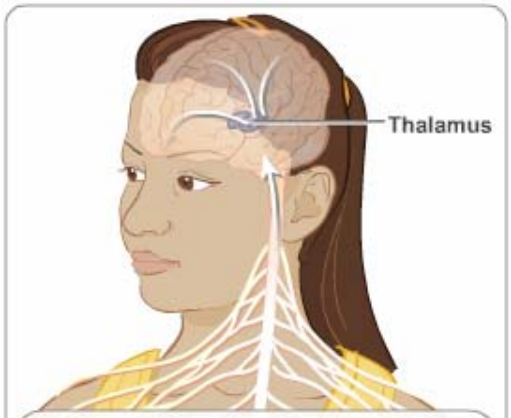
Designing the Site

Adolescent Modules

- Introduction
- About Arthritis
- Understanding Diagnosis
- Treatment
  - Managing symptoms
  - Managing stress
  - Learning to use relaxation
  - Knowing about medications
  - Learning to use distraction
  - Knowing about other therapies
  - Learning to manage thoughts
  - Therapies, self-monitoring and supports
  - Your lifestyle
- Looking Ahead

Treatment – Managing My Symptoms

- Goals of session
- What is Pain?
  - How we feel pain (animation)
- Managing your pain
  - Your pain can be changed
    - Medications for Pain
      - Types of pain medicines
      - How to take pain medicines
    - Physical methods to treat pain
      - Heat
      - Cold
      - Massage
      - exercise
    - Coping strategies for pain
      - Relaxation (audio clips)
      - Distraction
      - Changing the way you think
- Setting goals: Your plan for managing your symptoms
- Managing your symptoms: What you have learned (Dr. Know Quiz)



TRANSMISSION

From the spinal cord, the messages are sent to the thalamus. The thalamus is like a switchboard – it passes the information from your body to the brain.

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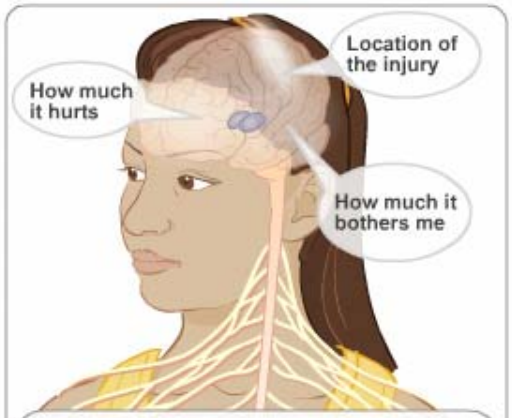

PAIN EXPERIENCE

The pain messages are processed in the brain, where all the information such as previous pain experiences, feelings, and memories are put together.

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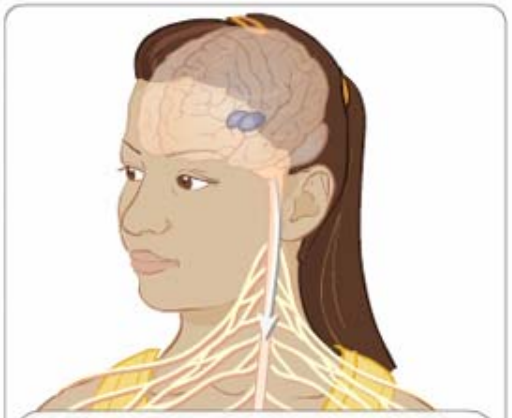

MODULATION

The brain controls the incoming and outgoing signals. These signals can reduce or increase the pain messages. That means that there are things you can do to reduce pain.

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INCREASING PAIN MESSAGES

Pain messages can be increased by not getting enough sleep, having tense muscles, doing too much or too little exercise, or feeling anxious or worried. These will make your pain hurt more.

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DECREASING PAIN MESSAGES

Pain messages can be decreased by medicines, relaxation, distraction, heat, cold, massage, and exercise. If you put ice on an injury, the new signals from the cold turn down the original pain message, and you may feel less pain.

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MODULATION: PUTTING IT ALL TOGETHER

Have you ever played a sport that you really liked and you've been injured during the game? Maybe you hurt your ankle or knee, but you distracted yourself to finish the game.

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HOW DO ANTI-INFLAMMATORY MEDICINES WORK?

A step-by-step guide.

CLICK TO START

Inflammation due to arthritis can be treated with many types of medication. Anti-inflammatory medicines, such as ibuprofen or naproxen help to reduce inflammation and can also be used to treat pain and fever.

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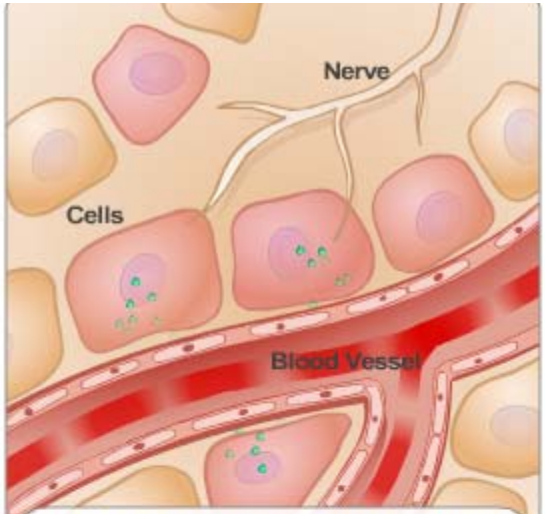

When cells in your body are injured, like what happens in joints with arthritis, they make and release substances that cause inflammation. These substances act on the blood vessels and other cells, making the vessels bigger and leaky.

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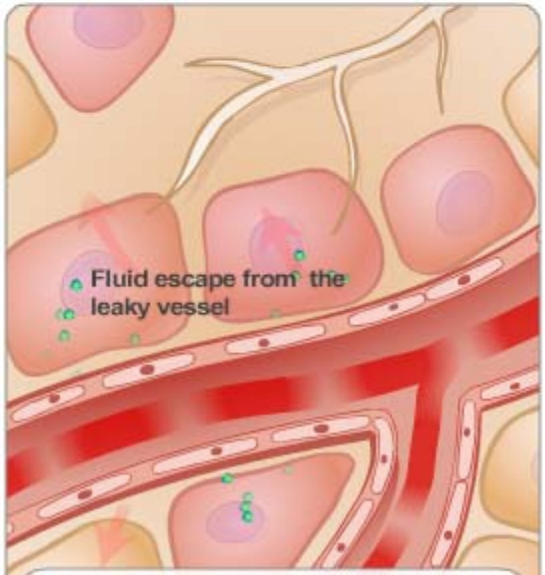

The leaky blood vessels then lead to increased fluid in your joints. This causes the joint to be swollen and feel warm.

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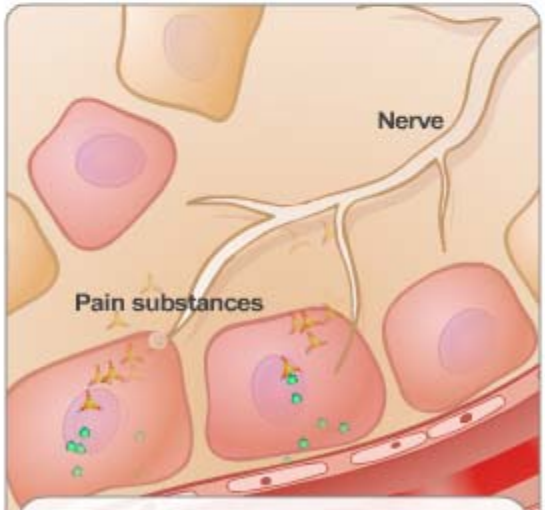

When cells are injured they also make and release other pain substances. Your skin contains nerves that are very sensitive to these pain substances. When the nerves detect theses substances they send pain messages up to the brain and you feel pain in your inflamed joint.

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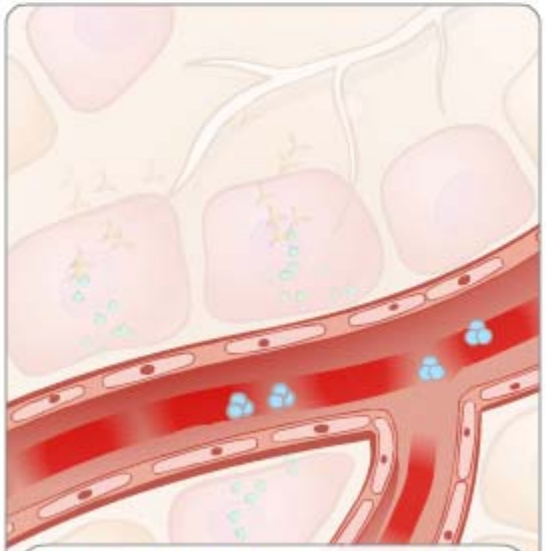

When you take anti-inflammatory medicines, they are absorbed into the bloodstream. From the bloodstream they can travel anywhere in the body to find the inflamed joint.

BACK NEXT

Learning to use Relaxation

Stories of hope…. Coping with pain

Another story of hope… Talking about pain

Parent Modules

- Arthritis: Impact on you and your family
- Letting go: Enabling your child to take control

Peer Support – Discussion Board

AboutKidsHealth April 21, 2006 trusted answers from SickKids

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AKH Diabetes Forum

Last post a few seconds ago by stever. 1 replies.

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2 minutes ago 3

stever

Joined on 10-18-2006
Posts 0

Hypoglycemia Resource

Reply | Quote | Delete | Edit | Favorites | Contact | Moderate

Do you know where i can locate a good resource where I can learn all about hypoglycemia and hyperglycemia with regards to my child's diabetes?

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a few seconds ago 4 in reply to 3

Dr. Know

Joined on 10-18-2006
Posts 0

Re: Hypoglycemia Resource

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Sure there is a great amount of information right on the AboutKidsHealth site:
http://www.aboutkidshealth.ca/clinicalAreas.asp?pageContent=DB-nh3-03d

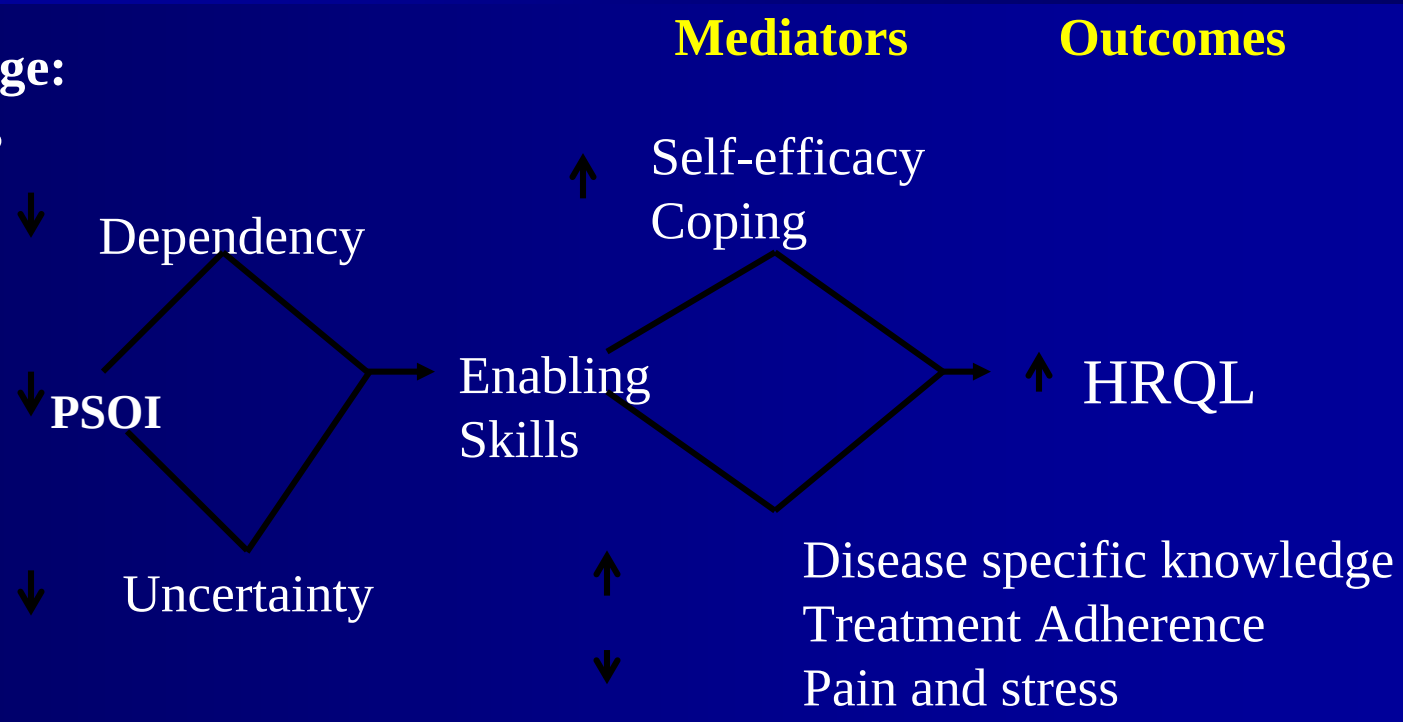
Report abuse Quick Reply

Ask the Expert

Goals and Desired Outcomes

Teens Taking Charge: Managing Arthritis On-line

- Self-management strategies
- Information
- Social support



Conclusion

- The internet will likely assume a major role in the delivery of self-management interventions for pediatric and adult patients with chronic health problems
- Serve as template for other pediatric chronic diseases
- This Internet based program can be used to educate other key stakeholders about childhood chronic illnesses:
  - health care professionals
  - lay audiences such as teachers and peers
- Internet based programs can be effective KT tools to help facilitate the collection, processing and targeted distribution of information about pain research to benefit patients and their families, clinicians, researchers, administrators, health care policy makers, and the general public *(Ko et al., 2004)*

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