How People Think About Cancer: A Mental Models Approach

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Background

Fear and complexity of cancer may impede understanding

People fear cancer: the diagnosis, the treatments, and the prognosis (Freimuth, Stein & Kean, 1989). That is true not only for adults, but also for children, who worry about getting cancer themselves (Chin, Schonfeld, O’Hare, Mayne, Salovey, Showalter & Cicchetti, 1998). Perceived seriousness is one of the major organizing factors by which people differentiate diseases (Turk, Rudy & Salovey, 1985), making cancer particularly salient. One possible source of the intense reaction to cancer risks is how easily worst-case cancer scenarios come to mind (Tversky & Kahneman, 1973). Another is the tendency of mass media to infuse cancer with fear, in part, by portraying cancer as inevitable and fatal (Clarke & Everest, 2006). Exceptionally bad experiences with cancer are more salient than cases treated early and effectively – many of which never come to others’ attention at all. As a result, people may overestimate cancer’s uncontrollability and the negative consequences that will follow a diagnosis (Silverman, Woloshin, Schwartz, Byram, Welch & Fischhoff, 2001). Such fear can be a barrier to screening (Subramaniam, Klosterman, Amonkar & Hunt, 2004) and contribute to choosing extreme treatments such as radical mastectomy among women who are candidates for breast-conserving surgery (Nold, Beamer, Helmer, & McBoyle, 2000) and prophylactic mastectomy among women with a family history of breast cancer, which they regret later (Montgomery, Tran, Heelan, van Zee, Massie, Payne & Borgen 1999; Peters, McCaul, Stefanek, & Nelson, 2006).

Another potential barrier to informed decisions about cancer is the sheer number and complexity of the decisions that might need to be made (Fischhoff, 2005; McCaul, Peters, Nelson, & Stefanek, 2005). There are many cancers, each posing choices regarding prevention, screening, and treatment – often requiring mastery of unfamiliar and uncertain domains. In
response to this complexity, health care educators and providers have labored to bring the facts of cancer to people, for example using decision aids aimed at patients facing cancer-related decisions (O'Connor, Fiset, DeGrasse, Graham, Evans, Stacey, Laupacis, & Tugwell P, 1999).

Where such interventions have been evaluated, the results have been mixed. Although patients rate complex decision aids as more helpful than simpler ones, their actual knowledge of cancer is similar with both (O'Connor, Stacey, Rovner, Holmes-Rovner, Tetroe, Llewellyn-Thomas, Entwistle, Rostom, Fiset, Barry, & Jones 2001).

Many agencies try to raise awareness of cancer, with actions like community events and public service announcements. Unfortunately, that well-meaning strategy may undermine the decision making of individuals who lack an overall understanding of cancer risks. For example, they may disproportionately increase cancer’s perceived risks, without creating a balanced appreciation of the control options. Of course, awareness can have benefits as well: increasing citizens’ demands for cancer research, eliciting compassion for survivors and those who have lost loved ones, and promoting timely screening. Communication strategies must weigh these benefits against the risks of creating an unrealistic fear of cancer. They can only do that with a comprehensive view of the decisions that people face, accompanied by an empirically grounded understanding of the beliefs and values brought to them. Without such perspective, communications risk rousing fearful emotions, without providing the factual knowledge needed to stabilize them.

**Understanding new information**

People try to make sense of the world around them, by integrating new information with existing beliefs. If those old beliefs are erroneous or confused, new information may be hard to process (Karasz, McKee & Roybal, 2003). Successful integration requires creating coherent
mental models, allowing people to make sense of what they hear and make consistent inferences regarding the situations that they face. Affording people such mental models requires understanding the beliefs that they already hold, in their intuitive formulations. Cancer communications structured around such existing sets of beliefs will be capable of building on correct beliefs and fixing incorrect ones. A scientific examination of lay beliefs should focus on the topics identified by cancer science as most relevant to achieving the goals that matter most to people. The mental models approach seeks these ends by integrating decision theory and behavioral research (Morgan, Fischhoff, Bostrom & Atman, 2001).

In past work, we have focused on the facts most relevant to specific cancer-related decisions, including ones involving prosthetic breast implants (Byram, Fischhoff, Embrey & Bruine de Bruin, 2001), exposure to carcinogenic household chemicals (Riley, Fischhoff, Small & Fischbeck, 2001), and the capabilities of mammography (Silverman et al., 2001). Each application typically focused on one or two aspects of the complex processes by which a particular cancer risk is created and controlled. However, each such choice is also embedded in people’s general beliefs about the processes creating and controlling cancer risks. For example, people care about risk factors because they worry about what might happen if they got cancer. Those in treatment often wonder how they got their cancer. And so on. Narrowly targeted communications may not provide needed context, leaving people with disparate beliefs, loosely organized around whatever overall mental model of cancer they happen to have. The resulting communications can be inefficient, by starting from scratch each time, and ineffective, by creating a fragmented and confusing overall picture, making people feeling overwhelmed by a problem that they can’t get their minds around. More comprehensive, basic education about
cancer can provide broader understanding, which serves as a basis for future, more specific 
messages (Schonfeld, Bases, Quackenbush, Mayne, Morra & Cicchetti, 2001).

Consequences of broad misconceptions

Without basic understanding of a domain, people have difficulty using whatever 
knowledge they do have. For example, experiences with minor diseases are sometimes 
inappropriately generalized to major diseases, resulting in misleading mental models (Lau & 
Hartman, 1983). In the context of cancer, that might account for the tendencies to blame general 
targets, such as stress and diet, and adopt unsuitable treatments, such as antibiotics or insulin 
(Payne, 1990). During the 1990s, most women followed the debate about routine mammography 
screening for women aged 40-49, but many believed that the only drawback to such screening 
was the cost to insurers, failing to recognize the increased risk of false positives (Woloshin, 
Schwartz, Byram, Sox, Fischhoff & Welch, 2000). That misunderstanding is consistent with a 
mental model in which all tumors grow rapidly (Carlsson & Strang, 1997).

These facts are not hard to explain. However, they do need to be conveyed in a way that 
contributes to a coherent, accurate mental model. Thus one might build on the standard approach 
of developing communications focused on changing specific behaviors (e.g., Hornik, 2003) by 
embedding them in a broader context. Here, we provide such complementary research, by 
seeking to identify a common conceptualization that will help people to interpret decision-
specific communications and to make appropriate inferences in situations where relevant, 
authoritative communications are absent.

National Cancer Institute’s Challenge Goal

In 2003, the National Cancer Institute (NCI) described its Challenge to the Nation: “to 
eliminate the suffering and death due to cancer” (von Eschenbach, 2005). More specifically, the
Institute committed itself to reducing the burden of cancer, casting it as no longer mysterious and frightening, but as a challenge that was being overcome through progress in research and practice. Implicitly, the Institute asked the public to stop hoping for the elusive “cure” for cancer and, instead, to fight cancer at each stage of the process: preventing it, delaying its onset, slowing its progress, or living a healthy, productive life with it (see Culliton, 2006, for a similar perspective.)

This reformulation requires a major shift in public understanding of cancer – one that is unlikely to be achieved with piecemeal communications about specific cancer risks, screening techniques, and treatments. Pursued in isolation, these messages may undermine the desired transformation, by reinforcing the existing mental models that they evoke. The Institute’s strategic formulation is, necessarily, quite abstract. An intermediate conceptualization is needed to create the bridge between the general framework and more specific content that can guide inferences and decisions, in a way that is faithful to both the scientific evidence regarding cancer and people’s intuitive ways of thinking. Given the heterogeneity of the processes that need to be understood, we propose that such a model should be metaphoric, providing a general script for organizing narratives about cancer.

A useful metaphor would convey understanding about how cancer acts in the body and can be treated. It would be neither the cancer metaphor denounced by Susan Sontag (1978) as blaming victims and mystifying disease, nor the “military metaphor” of the War on Cancer (Penson, Schapira, Daniels, Chabner, & Lynch Jr., 2004), which undermines the idea of living with a chronic disease caused by a body at war against itself (Skott, 2002). Like other heuristic devices, metaphors cannot provide complete accounts. At best, they can guide generally accurate inferences. As a result, a metaphor that works for the public might sometimes offend experts,
who can readily identify its limitations. Those experts would have to be convinced that: (a) a deliberately selected metaphor leads to better inferences and choices than the intuitively selected metaphors it replaces, and (b) a metaphor’s limitations are understood well enough to avoid mistaken inferences (e.g., by explicitly contradicting them).

Approach

The interviews. The research reported here implements the initial steps of a mental models approach, describing lay beliefs in their intuitive formulations, focused on cancer-related issues identified by NCI domain specialists. These issues cover the full range of cancer concerns, including risk factors, disease progression, symptom identification, test choice and interpretation, treatment risks and benefits, recovery, and risk of death. We use the mental models approach to interviewing, in which open-ended questions focus interviewees with increasing specificity on the target issues. Participants are encouraged to express their full range of beliefs and concerns in their own words. The beliefs and language revealed in these interviews show conceptions and misconceptions that people bring to their cancer-related choices and to their interpretation of cancer risk communications.

With given research resources, such intensive interviews can reach a relatively limited sample. However, they provide the foundation for developing structured knowledge tests that could be administered to larger samples, capable of estimating the population prevalence of beliefs (e.g., Bruine de Bruin, Downs, & Fischhoff, in press; Palmgren, Morgan, Bruine de Bruin, & Keith, 2004) and interventions targeting specific knowledge gaps and misconceptions (e.g., Downs, Murray, Bruine de Bruin, Penrose, Palmgren & Fischhoff, 2004). The interviews
identify not only the content of such tests and interventions, but also the language that they should use.

The metaphors. One goal of this research was to identify metaphors that could bridge NCI’s strategic concept with specific inferences. To that end, we identified eight candidate metaphors, then examined how people apply each to six key cancer topics: risk factors, disease progression, symptoms, testing, treatment, and outcomes (recovery, recurrence, death).

Based on existing research and consultation with NCI experts, we anticipated finding that many people think of cancer as a kind of invasion by contaminants. Individuals relying on this metaphor may feel the need to remove every single cancerous cell – or else risk death. A contamination metaphor could also prime (useful or exaggerated) thoughts about exposure to hazardous chemicals. It would not prompt thinking about genetic predisposition. Thus, a contamination metaphor could be both useful (e.g., by reducing needless exposures) and damaging (e.g., by encouraging needless anxiety or medical treatment). Another possible metaphor views cancer as a natural process that might be delayed long enough to avoid cancer altogether. That metaphor might help people treat cancer as “just” a part of life, something to live with, rather than have it as an overhanging fear. However, it could also encourage fatalism, leading them to ignore preventive measures. Because the natural process concept is so central to the Institute’s thinking, we tested several metaphors representing it, in order to examine their intuitive appeal and associated inferences. We also chose metaphors suggesting less natural processes.

Methods

Participants
We completed telephone interviews with 30 individuals drawn randomly (by a market research firm) from a national sample, ages 18 to older than 75. Overall, 33% were white, 23% African American, 20% Asian, and 23% Hispanic. Approximately one-third of the sample reported having been diagnosed with cancer, all of whom had relatively mild and easily treated cases (i.e., without chemotherapy or radiation treatments), and were in complete remission. We also interviewed 10 community leaders who serve as cancer outreach communicators in diverse communities across the country. Of those, five were white, one African American, two Asian, and two Hispanic. Consent forms were approved by Carnegie Mellon’s IRB, and sent by mail or email, with any remaining questions answered over the phone. Differences between the responses of outreach communicators and other participants were minimal; as a result, we pooled responses from all 40 participants (except where noted).

**Materials**

We included a few key questions from a related national survey with a rigorously developed item pool, in order to compare our participants’ cancer knowledge with those of a nationally representative sample. The Health Information National Trends Survey (HINTS) was developed by the Health Communication and Informatics Research Branch of the Division of Cancer Control and Population Sciences as one product of the National Cancer Institute's Extraordinary Opportunity in Cancer Communications (Nelson, Kreps, Hesse, Croyle, Willis, Arora, Rimer, Viswanath, Weinstein, & Alden, 2004). HINTS has a nationally representative, Random Digit Dial (RDD) sample of adults 18 years and older. Like our study, it is administered in one-on-one interviews, eliciting open-ended responses that are then coded. We selected three of its key questions about cancer knowledge to include in our own interviews for comparison.
Our interview protocol began by asking participants to describe their understanding of cancer, focusing, in turn, on six domains determined through our consultation with cancer experts: Risk Factors (causing and preventing cancer); Symptoms (cues that might signal cancer); Testing (routine and diagnostic); Disease Progression, Treatments, and Outcomes (recovery, recurrence and death). Embedded in these general questions were three specific ones from HINTS. They tested knowledge about (a) general risk factors: “Can you think of anything people can do to reduce their chances of getting cancer?”; (b) specific risk factors: “Are there any changes people could make in their eating habits to reduce their chances of getting cancer?”; and (c) screening and testing: “What kinds of tests should people get to find out whether they have cancer?”

The interview protocol described eight metaphors, drawn from the research literature and expert input: (a) heart disease; (b) an infection by caused by a parasite, such as a tapeworm or a tick; (c) allergies, such as to dust or peanuts; (d) auto-immune diseases, “where the body attacks its own cells,” such as multiple sclerosis or diabetes; (e) the health problems that people get as their body ages, such as osteoporosis or dementia; (f) contamination with something toxic, such as lead poisoning or pesticides in food; (g) infections caused by a virus, such as measles or HIV; and (h) an accident waiting to happen, “such as running with scissors or driving a car that is in very poor condition.”

Procedure

Interviewees were asked to start by describing their beliefs regarding each of the six domains (e.g., "Can you think of anything people can do to reduce their chances of getting cancer?" "Can you tell me what you know about how cancer is treated?"). They were asked to expand on each belief that they provided (e.g., how a behavior reduced or increased risk, how a
treatment worked). Prompts continued until interviewees reported having nothing more to add. For each domain, interviewees were asked to think of another disease that was like cancer in that respect, then to describe similarities and differences. They were then asked which of the diseases that they had mentioned was most similar to cancer, and why. They were invited to share any personal experience with cancer, if they felt comfortable doing so.

Finally, interviewees considered three of the eight metaphors for cancer, drawn according to a partial Latin-square design. For each, they were asked what conclusions they would draw upon learning that a new disease “was kind of like” it (e.g., kind of like being contaminated with something toxic) and how the metaphor did and did not fit cancer. They rated how well each metaphor fit cancer on a 1-5 scale, from “very different” to “very similar.”

Qualitative content coding

Interviews were transcribed verbatim and each sentence coded into the protocol’s topics. A set of codes was created for each, starting with those used by HINTS, then supplemented with new concepts mentioned in the interviews. Any statement that reflected an incorrect assertion or a misunderstanding of a concept was coded as such.

Results

Overall picture: Fragmentary mental models

Risk factors

When asked what people could do to reduce their chances of getting cancer, 63% of interviewees mentioned “not smoking” (Table 1). Most (78%) mentioned improving nutrition (e.g., “eat better,” “live a healthy lifestyle”), although they often could not elaborate how or why such a change would be helpful, beyond just listing a couple of basic rules (e.g., eat more
vegetables or less red meat; Table 2). When asked for a specific dietary change that should reduce cancer risk, 30% could not name even one.

Only 30% mentioned environmental causes as contributing to cancer risk. A mere 15% mentioned exposure to sun (despite the extensive publicity on those risks). Some of those who mentioned environmental causes expressed a lack of control (e.g., "Don't breathe the air, I guess." "I don't know what you can do about that, other than, short of moving away."). A few mentioned stress as a cause of cancer or avoiding stress as a way to prevent it.

Although some major cancer risk factors were mentioned by many participants, few could explain how those factors contributed to cancer. Indeed, most did not even try, merely saying that they did not know, as illustrated in these quotations:

- I know that diet affects many other illnesses, diabetes and heart and so forth, but I don’t know about cancer. (Hispanic male, age 65-74, no cancer history)
- I don’t know much about skin cancer, but I went to tanning beds a lot, and I have lots of moles now, and everyone is telling me that I should go and get them checked because, you know, they say that tanning beds cause cancer. (Hispanic female, age 25-34, history of cervical cancer)

These results indicate a tenuous grasp of cancer risk factors. Even when interviewees knew about a risk factor, they could rarely say very much about its mechanism of action. Without such knowledge, it can be difficult to select and implement effective risk-reduction behaviors, respond to changing circumstances, overcome obstacles, or follow debates about conflicting evidence. For example, without knowing what constitutes a "better" diet, people may waste their energies on fads, possibly even increasing their cancer risk. Conversely, not knowing
how a recommended behavior reduces cancer risk may make it easier to make excuses for stopping it.

**Symptoms**

Interviewees offered various symptoms. About half (45%) said, at some point during the interview, that it is possible to have cancer without knowing it, often sharing stories about people who were surprised to discover that they had cancer. About a third (35%) said that people can have cancer without any symptoms at all. Symptoms ranged from very specific, the most common being lumps in the breast, to very general, such as ill health. Typically, symptoms were seen as a prompt for additional evaluation, rather than as proof of cancer.

- The easiest thing is to just go and get tested for your symptom, what the symptom is, and then you can find out why it’s there. (Asian female, age 25-34, no cancer history)

- They wouldn’t think they had cancer until they saw something, or felt something … unless they saw a growth or something like that. (Asian male, age 25-34, no cancer history)

Most interviewees said that they would not get cancer tests after every suspicious cough or headache, but could not specify their decisions further. Without a better mental model of symptoms, there seem to be substantial risks of both excessive testing and missing opportunities.

**Testing and screening**

On average, interviewees provided 2.6 different tests for cancer, with mammography being the most common (Table 3). In one of the few differences from lay interviewees, our cancer outreach specialists made fewer statements about the general need for testing or screening, $t(36) = 3.62, p < .001$, and more about specific screening recommendations, such as
testing people at high risk, t(38)= 2.13, p<.05, teaching people more about cancer, t(25)= 2.12, p<.05, and distinguishing among disease processes, t(25)= 2.12, p<.05. Interviewees generally described testing in terms of following up observed symptoms or engaging in routine screening practices, especially for those at higher risk.

- I have heard of people who have had a sore throat or a problem, thinking it was just a virus that they had or a cold and seek medical advice and find out that, sure enough, they got cancer of the throat or the esophagus or whatever. (Hispanic male, age 65-74, no cancer history)

- Until my doctor found it out, and in my case I have this prostate thing, it was my doctor who found it out and said, hey, you have something of a cancer in your prostate. (Asian male, over 75, history of prostate cancer)

Such descriptions reflect an image of cancer "lurking" in the body, surreptitiously polluting it and needing to be found before it is too late. Although this metaphor could prompt people to get screened regularly, its vagueness could contribute to problems like the common belief that any physician, performing any kind of examination, could discover a lurking cancer. Few saw drawbacks to testing, apart from possibly receiving the unpleasant news that one has cancer. Only 15% mentioned the risk of false positives. Although many listed cancer-specific tests, some believed that there was one test (usually a blood test) that could screen for all cancers. If people exaggerate the comprehensiveness of screening, they may exaggerate the extent to which no news is good news, leading them to neglect additional screening and protective behaviors.¹

¹ An analogous misconception is found with tests for sexually transmitted infections: many people believe that any blood sample will automatically be tested for HIV and that a pap smear
Disease progression

Few interviewees had any confidence in their understanding of how cancer develops. Many answered simply, "I don't know," to basic questions about how cancer starts (35%) or progresses (21%). Those who did answer typically had little to say about how cancers begin, using rudimentary language about "bad" cells. Most described cancer as growing, spreading, or multiplying, with general phrases like “it just continues to grow." Few gave enough biological detail to indicate any real understanding. About a third (35%) mentioned treatments, saying that cancer will grow if nothing is done about it. Those who mentioned risk factors typically cited the same ones for cancer’s initiation and progression, with the most common being smoking and exposure to the sun. African Americans talked more than others about how cancer can progress before it is noticed, $F(3,35)=3.33$, $p<.01$, and about their need for more information, $F(3,35)=4.77$, $p<.01$. Only Asian interviewees talked about the importance of a positive attitude or religion in preventing cancer, $F(3,35)=3.01$, $p<.05$. Very few mentioned the possibility of cancers growing at different rates.

- I have to suppose that it’s like an infection that just starts in one spot and continues to spread into other parts of the body or into the rest of the organ it started in, for instances, the lung or colon or whatever. (Hispanic male, age 65-74, no cancer history)
- I think in youngsters [there is] much quicker expanding or spread, well adults it may spread in other areas; it may spread in others; maybe if they have it in the lungs, they may have it in their brain or their back or their neck. (Asian female, over 75, no cancer history)

detects sexually transmitted diseases other than HPV, the virus that causes genital warts (Bruine de Bruin, Downs, Fischhoff & Palmgren, 2006).
• So I can’t really say how it really gets start[ed] because it is just a puzzle of questions that’s in the body when the chemicals and your body cells are malfunctioning, and nobody really knows what type of exposure these people have had during their life that have cause this or rather has gone down from generations to generations. (African American female, age 55-64, no cancer history)

Treatments

Most interviewees listed at least two ways to treat cancer, with the most common being surgery (73%), radiation (73%), and chemotherapy (68%). All mentioned at least one method, except one individual who talked about the importance of maintaining a positive attitude and "accepting death" as a possible outcome. Interviewees tended to prefer surgery because it offered a chance of removing all of the "cancer cells," while recognizing that cancer can come back if "there was something left" or "it had spread to different parts of the body." They saw less value in chemotherapy and radiation, because they did not seem to offer hope of complete eradication (e.g., "[These treatments] more or less prolong suffering and the pain, and [a patient] must see the doctor more often, go to chemotherapy."). Most people believed that cancer could be cured (79%). Those who believed in a cure also talked more about factors affecting treatment effectiveness, t(36)= 2.74, p<.01, and about the importance of detecting cancers, t(36)= 2.07, p<.05. Those who did not think that cancer could be cured did not appear to value strategies for slowing or containing it, t(29)= 2.11, p<.05.

• I don’t have any idea how [medications] know where to go, but once you get it in your blood stream, it goes throughout your whole body, then attacking the cancerous growth. (White male, age 65-74, history of prostate cancer)
- I guess the surgery, like, kind of picks it out and the medication goes through your body, blood and fluids, to keep it out. (African American female, age 35-44, no cancer history)

- Surgery I think is better, if a person can stand the surgery, because that’s once and for all thing. (Asian male, over 70, history of prostate cancer)

**Outcomes**

Most interviewees (78%) understood that “remission” meant (just) containing growth, which some explicitly described as different from being cured (e.g., "When I am not in remission anymore, I don't have cancer anymore."). They believed that people could do very little to prevent a re-occurrence, other than perhaps “just follow what the doctor says.” White and African American interviewees were less likely to have misconceptions about remission (7% and 13%, respectively), compared to Hispanic (25%) and Asian (56%) interviewees, $\chi^2(3)=8.28$, p<.05. A common mistake was confusing remission and recurrence. Most (72%) mentioned the possibility that cancer can recur, often believing that it happened when the cancer hadn’t been treated properly and could come back elsewhere in the body. Nearly all mentioned that cancer was fatal, typically in general terms.

- I think remission means that it was there, but then it stopped for a while, and then it came back. (Hispanic female, age 25-34, no cancer history)

- It feels like there’s a way to cure cancer there, but if it’s inherent in the person on some level – I don’t know, genetically or something like that – and it feels like, without some sort of gene therapy, then that form of, that cancer is incurable. (White male, age 25-34, no cancer history)
• So why did it come back, if they had surgery or radiation, and it was supposed to be gone. (African American female, age 55-64, no cancer history)

The older the interviewees were, the more likely they were to know that cancer can return after it has gone into remission ($r=.41$) and the more often they talked about the possibility of having cancer without knowing ($r=.39$). They were more likely to cite the importance of scientific or other credible evidence ($r=.50$) and less likely to hold misconceptions about remission ($r=-.52$). They talked more about cancer being pervasive ($r=.48$) and having unknown risks ($r=.34$).

**Experience with cancer**

Comparing the cancer outreach workers, cancer survivors, close family members of individuals with cancer, and interviewees with no close experience revealed surprisingly little effect of experience on general understanding. The less experience interviewees had had with cancer (either personally or through people very close to them), the more often they mentioned factors affecting the cancer process (such as differences between people or types of cancer, $r=-.55$) and the more often they mentioned that risks were not known ($r=-.31$). This may suggest that such variability is appreciated in the abstract, but becomes less relevant once there are particular examples focusing one’s thoughts.

Outreach workers did not appear to have greater cancer knowledge than the lay interviewees, as measured by either the HINTS knowledge scores or the misconceptions revealed in the rest of the interview. Interviewees who had had cancer also had beliefs similar to others, except that (a) they gave fewer caveats in their description of the cancer process, mentioning less often that the process depends on various factors, $t(36)=2.64$, $p<.05$; (b) they mentioned fewer
HINTS factors that could reduce cancer risk, \( t(38)=2.05, p<.05 \); and (c) they more frequently discussed asymptomatic aspects of cancer, \( t(38)=2.20, p<.05 \).

**Appeal of metaphors**

When asked to name conditions similar to cancer, interviewees most frequently mentioned infectious diseases (68%, including HIV, Hepatitis, TB and the common cold), followed by heart disease (45%), and autoimmune diseases (43%). Only one interviewee indicated contamination (citing asbestos). About one-fifth could not pick any metaphor as most similar, unable to compare cancer to any other diseases. When asked how their volunteered metaphors applied to each of the six different aspects of cancer that we asked about, the ones seen as having the most similar risk factors were heart disease and autoimmune disease. For disease progression, symptoms, treatment, and outcomes, infectious disease was seen as the most similar metaphor. For testing, heart disease was most similar. Across all aspects of cancer, however, the percentage of interviewees who could not name any metaphor remained relatively large.

After the interview section on different domains of cancer, where interviewees could generate their own metaphors, we asked them to discuss how well cancer fit three focal metaphors in terms of the six domains. Table 4 shows these metaphors in order of judged similarity to cancer. The second and third columns describe ways in which cancer seemed similar and different. The metaphors are listed in descending order of perceived similarity to cancer:

(a) An accident waiting to happen, “such as running with scissors or driving a car that is in very poor condition,” was judged to be similar to cancer mostly in terms of being preventable. Interviewees believed that the metaphor did not explain genetic factors of cancer as well.
• If you know that a disease is in your family and you don’t do anything about it, then it is an accident waiting to happen (Hispanic female, age 45-54, history of skin cancer)

• If you are educated, you can almost keep, maybe, maybe you can keep it from happening by education and, and food and diet and, and how you live and how you, you know, how you take care of yourself. [But if] somewhere in that family somebody had cancer [in] their genetics, it’s there, that certain disease. (African American female, over 75, no cancer history).

• Other than lung cancer I think the rest of the cancers are just there and it just happens. (60-year old white male with history of prostate cancer)

(b) Contamination with something toxic, “such as lead poisoning or pesticides in food,” rarely arose spontaneously, but was strongly endorsed when interviewees were asked explicitly about its degree of similarity. One recurrent analogy was exposure to toxic substances in the environment, which then caused abnormal cell growth, which should be completely removed from the body and which will return with continued exposure. For example:

• A foreign object, a foreign substance in the body that shouldn’t be there. (Hispanic female, age 25-34, history of cervical cancer)

• It could be something in the air. They could have been in Vietnam and got agent orange. You know, that caused the cancer. (African American male, age 55-64, history of prostate cancer)

• [It’s similar] because you are still trying to go in there … to get rid of the bad cells vs. the good cells or the bad whatever is in you, trying to take over. (White female, age 35-44, no cancer history)
[It’s different] because it’s an exogenous cause as opposed to cancer being an endogenous cause. (White female, age 45-54, no cancer history)

(c) Auto-immune diseases, “where the body attacks its own cells,” such as multiple sclerosis or diabetes, were judged to be similar to cancer in that they could recur after they had been treated. Although cancer was seen as a more serious disease, some interviewees believed that it was more localized, hence easier to treat.

- It might be curable, but yet it could come back. And there might be ways to live [with] it, but you know, still keep it under control. (White female, age 35-44, no cancer history)

- You don’t actually know it’s in there, because a lot of people walk around with cancer everyday and don’t even know it…. [It’s also similar] in the way it is treated, the therapy, because you don’t know if it has been eliminated completely from the body. (Hispanic female, age 45-54, history of skin cancer)

- To me, they might be a little similar because they both take medicine that controls it, but then there’s that time that the medicine doesn’t work anymore so it kind of takes over on its own. (Hispanic female, age 25-34, no cancer history)

(d) Heart disease arose spontaneously with some frequency but was not rated as particularly similar to cancer. Typical references invoked similarities to cancer in terms of both having behavioral, genetic, and environmental risk factors, as well as being hidden problems that grow progressively worse. Cancer, however, was seen as less sudden, more difficult to prevent, and more difficult to treat.

- They both feel like the kind of disease where if you have a [family] history of it then you’re more at risk and you should think about this. And there are
behavioral, I think, things that you can do like you can smoke or you can become obese. (White male, age 25-34, no cancer history)

- If you don’t take care of it, it will progress to death, you have to do something. [And] if you are prone to heart disease, just like you are prone to certain cancers there’s always a chance of reoccurrence. (Hispanic female, age 35-44, no cancer history)

(e) An infection caused by a virus, such as measles or HIV, was seen as similar in that it can be treated, but come back again. HIV was singled out for similarity because of its perceived lethality. Interviewees stressed, however, that the disease processes are different.

- With cancer, if treated properly and caught in time and everything, it, you could be in remission, so that means it will go away. Same with the virus, if treated properly it will go away. You will be cured. (African American female, age 35-44, no cancer history)

- There is somebody that has it that passes it on to you, in one form or another, either airborne, fluid borne, and it’s given to you or passed on from person to person vs. cancer, cancer is not passed on that way. (Hispanic female, age 35-44, no cancer history)

(f) Parasitic infections, such as those caused by a tapeworm or a tick, were seen as similar in terms of the role of environmental exposure, and the possibility of spreading through the body and growing through cell division. The most important differences were cancer being more difficult to treat and having no cure.

- They both function the same way I guess. The cell division or whatever multiplication process they have or whatever, whatever mechanism it is that
causes them to grow. They both spread. The cancer would spread. The parasite
infection would spread. (White male, age 65-74, history of prostate cancer)

- You might be able to be cured for a while, but eventually you’re not going to cure
  that all together. I think that with the parasitic infection, you’ll, you’ll be able to
cure it. (African American female, over 75, no cancer history)

(g) The health problems that arise as people’s bodies age, such as osteoporosis or
dementia, were seen as similar in that they occurred systemically, with the body's defense system
becoming less able to protect it. The most commonly noted difference referred to cancer
affecting people of all ages.

- You know, when the cell divides, and with the wear and tear of the environment
  and what you do to your own body could make these changes occur. (African
  American female, age 35-44, no cancer history)

- Cancer doesn’t come with old age, cancer is something that develops in your body
  (African American male, age 55-64, no cancer history)

(h) Allergies, such as to dust or peanuts, were seen as least similar to cancer, although
some participants mentioned environmental exposure as a similar.

- Allergies in my understanding are very, very treatable. Whereas even with all the
  advances made by, in the area of the study of cancer, they can’t get them all. They
can’t cure them all. (White male, age 65-74, history of prostate cancer)

- I guess it could be similar because it’s environmental (White male, age 55-64, no
cancer history)
The ailments invoked by each metaphor were seen as different from cancer in their severity, often emphatically so. Even participants with personal cancer experiences, which in this sample had been mild cases in remission, felt that cancer was extremely severe and deadly.

HINTS questions

Our sample was designed for diversity (of experience and background), rather than representativeness. Nonetheless, their knowledge of cancer is broadly similar to that found when the HINTS question were administered to a representative U.S. adult population (Nelson et al., 2004). Table 1 shows mentions of the risk factors listed in the coding scheme. Our participants mentioned slightly more factors overall, possibly reflecting differences in population, interview, or application of the coding scheme. One striking difference is our interviewees’ lower emphasis on smoking. One possible methodological reason is that this was the first question asked in our survey, whereas it was the second question in the HINTS interview, directly following a question mentioning smoking as a cause of death.

This similarity extends to beliefs regarding changes in eating habits that might reduce cancer risk (Table 2). Our participants mentioned about the same number of factors as HINTS interviewees, with similar relative frequency. HINTS posed this question only to those who mentioned diet as a way to reduce cancer (in response to the first question), whereas we posed it to all participants. In part because most of our participants mentioned diet as a way to reduce cancer, following the HINTS protocol would have made little difference in the results.

Interviewees in our interviews and HINTS produced somewhat different descriptions of tests for cancer (Table 3). Here, the HINTS protocol may have made a difference, as the question was posed only to the 5% of participants who mentioned getting screened or tested for cancer as something that people could do to reduce their risk. The seemingly greater knowledge of HINTS
interviewees about tests might reflect this restriction to those mentioning testing in the first place. More of our participants (20% vs. 5%) mentioned screening. However, they are too small a group (8) to compare. One suggestive result is that those who did not volunteer screening were more likely, when asked, to talk merely about generic tests (e.g., blood tests, x-rays, MRIs, CT scans).

Discussion

Most interviewees knew very little about cancer. On the surface, some seemed relatively well informed, talking about risk factors, eating habits, and treatments, using words like “remission.” However, further probing showed that many knew the terms, but not the underlying concepts. Their mental models were typically incomplete, inconsistent, and error-laden. They were particularly confused about risk factors (e.g., what constitutes a "better" diet), testing and screening (e.g., assuming that non-specific blood tests performed by any physician would be able to discover a lurking cancer), disease progression (e.g., being unclear about how cancer starts), and treatment (e.g., emphasizing the need to remove all cancer cells).

Without such critical details, people cannot act on their beliefs, communicate effectively with physicians and family, or make sense of their circumstances. They need accurate mental models in order to make effective decisions regarding eating habits, screening, treatment, and other cancer-related choices. Both the lack of such mental models and the awareness of that absence contribute confusion to the fear raised by cancer.

Problematic metaphors

The worst news in these interviews was that a metaphor with great intuitive appeal was also quite inappropriate, in terms of fitting the facts of cancer and facilitating emotional equanimity regarding the threats. Interviewees strongly endorsed the contamination metaphor
when described to them in the final section of the interviews. Unfortunately, this metaphor implies the need to remove cancer risk entirely. It raises impossible demands (and sometimes expectations) for screening and treatment procedures. Commercial “full-body” screening centers exploit this misconception by promising detection without warning against false alarms. Focusing on contamination suggests few prevention measures, except for avoiding any exposure to perceived carcinogens. It leaves a stain on those who have, or think they have, any semblance of cancer. Moreover, the details of the interviews suggested that other metaphors may be acceptable to people. Not only is contamination emotionally unsatisfying, but people also realize that decontamination is not a realistic aspiration. Such lack of hope may underlie much of the fear of cancer, partially contributing to failures to screen and devastation following diagnosis.

The metaphoric image of cancer growing and spreading that emerged from people’s descriptions of disease progression might provide the foundation for a more complete mental model, incorporating ways in which that growth can be slowed, stopped, or reversed. However, very few interviewees currently saw any chance of influencing disease progression, “once cancer has started.” Indeed, their default belief appears to be that cancers grow quite quickly. That fear was expressed by people who had never been diagnosed with cancer, as well as women who had had cervical cancer and men who had had prostate cancer. The cancer survivors almost uniformly saw themselves as lucky to have caught it early. The sole exception was a man who believed that his prostate cancer had been slow growing.

Thus, it may be feasible to refine the widely shared growth metaphor by adding the idea of differential growth rates. That would accommodate the realities of tragically fast cancers, inherently slow-growing cancers, and treatments slowing growth rates. Conveying the specific implications of differential growth rates would have to confront the well-documented difficulty
that people have in estimating how risks accumulate through repeated exposure (e.g., Shaklee & Fischhoff, 1990). That difficulty leads them to underestimate both the cumulative effects of exponential growth and the impacts of changes in growth rates (Fischhoff, Bostrom & Quadrel, 2002).

Interviewees’ focus on eradication when describing treatments seems to reflect a mixture of belief (that eradication is essential for effective treatment) and desire (for a way to put cancer out of mind). As a result, it may be a potent obstacle to improving their understanding of cancer. People need an alternative organizing metaphor that not only leads to accurate inferences, but also provides emotional relief. Some grounds for crafting more nuanced messages can be found in the detailed text of the interviews. For example, many people describe eradication as more hope than reality, suggesting that they might embrace a growth model if it were expressed in a way that conveyed a realistic feeling of hope. That expression would have to address the common belief that when cancers are not removed entirely, re-growth will be very fast and uncontrollable. That belief was found even among people who had received seemingly successful cancer treatments, reinforcing the overwhelming role of fear.

One metaphor that was introduced to take advantage of the idea that cancer might grow slowly and be confined to later life was that of the body aging. Interviewees were particularly resistant to this idea, as were the domain experts, although for somewhat different reasons. Experts felt that such a metaphor confused natural growth and aging of cells with the unnatural, uncontrolled growth of cancer cells. Interviewees were more disturbed by the fact that cancer does not only affect the elderly but can happen even to children. Thus, any potential this metaphor might have had to convey particular ideas of slowing but not curing cancer is undone by its inherent differences and the overwhelming reluctance to consider it. Two other metaphors
that were included to explore the sense of the body reacting to processes inside it, allergies and parasitic infections, were also met with a lack of enthusiasm. The ease of treating both of these ailments set them apart from cancer, and few similarities were seen to redeem them.

**Useful metaphors**

As seen in the contrast between Table 4’s rating and the frequency with which metaphors were produced spontaneously, many participants could see the relevance of many metaphors, once they were presented. Particularly promising alternatives include (a) heart disease, (b) "an accident waiting to happen," (c) auto-immune disease, and (d) infectious disease. Among these, heart and infectious disease were most often evoked without prompting.

Interviewees intuitively saw how heart disease had risk factors similar to those of cancer and could have equally sudden onset. As an organizing metaphor, heart disease has the further benefit that some behavioral, life-style changes may protect against both heart disease and cancer (although some drugs may decrease one risk at the price of increasing the other). Unfortunately, interviewees could not easily apply the heart disease metaphor to other aspects of cancer. A communication program built on this metaphor would have to find intuitively compelling ways to address the presence of affected areas throughout one’s body, increasing growth and susceptibility with age, and the likelihood of re-growth and re-occurrence of disease after treatment. Conceptualizing heart disease as arteriosclerosis might provide some of these goals, at least for those familiar with it.

Another intuitively appealing metaphor, "an accident waiting to happen," may have more general promise. It suggests that many factors must come together for cancer to arise. Conversely, there may be many different things that one can do to reduce that risk. Although these steps cannot eliminate all risk, they might reduce it to an emotionally manageable level,
while giving the feeling that one has acted prudently. In order to use the accident metaphor effectively, as a guide to cancer-related decision making, people need authoritative information about what the risk and protective factors are, presented in an intuitively appealing way. Feelings of empowerment will be undermined if they have to sort through conflicting claims or, worse, discover that they have unwittingly invested in strategies lacking scientific support or having trivial impact. (Witness the recent controversies over pain-killing drugs and hormone replacement therapy.) A communication challenge inherent in the accident metaphor is avoiding producing a disorganized list of seemingly unrelated facts. Some internal organization is needed if communications are to transform existing mental models into frameworks for broader understanding.

Autoimmune disease has promise in promoting understanding of cancer, especially in its tendency to recur and occasional lack of symptoms while damage may be done to the body undetected. The need to follow through in treatments over the course of time may be reinforced by analogy to chronic, autoimmune conditions. Infectious disease, including the flu, HIV, TB and others, can be useful especially in their variability. Interviewees focused on the lethality of HIV in making a case for its similarity, an association that perhaps could be exploited by comparing less lethal cancers to more mild diseases. While the prognosis for lung cancer may call to mind HIV, cervical cancer may have a better comparison in a highly treatable infection that requires quick treatment.

Using metaphors to facilitate education

These preliminary data provide a well-grounded starting point to explore further metaphors that are promising, in terms of their ability to capture difficult concepts and provide a framework for education about cancer. The metaphors will need to be fleshed out into a broader
explanatory capacity to determine whether they are not just compelling but can also facilitate understanding. Such a study would compare the best metaphors, along with a control group receiving a similarly intense exposure to conventional information, in their ability to improve understanding and to lead to correct inferences about new information. A good metaphor will not only make specific content easier to understand, but will provide a basis to make sense of new information in a way that is correct and useful. An in-depth study could identify possible applications of metaphors to education, and a randomized controlled trial could then pit metaphors against each other (and against a similar amount of general cancer information without any organizing metaphor) to determine viable strategies for educating the public about broad cancer processes and prevention. Finally, metaphors that appear particularly useful in helping people to understand cancer can be paired with more specific messages tied to relevant behaviors, in order to determine whether they enhance the effectiveness of directed communications and lead to more, better, or longer-lasting behavior changes.

References


Table 1. Responses to “Can you think of anything people can do to reduce their chances of getting cancer?”

<table>
<thead>
<tr>
<th>Risk factors and strategies</th>
<th>Interview responses</th>
<th>Population (HINTS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't smoke/Quit smoking</td>
<td>63%</td>
<td>59%</td>
</tr>
<tr>
<td>Eat better/Better nutrition</td>
<td>78%</td>
<td>51%</td>
</tr>
<tr>
<td>Exercise/Exercise more</td>
<td>48%</td>
<td>25%</td>
</tr>
<tr>
<td>Get a check up/Go to the doctor</td>
<td>33%</td>
<td>16%</td>
</tr>
<tr>
<td>Don't drink alcohol/Drink less alcohol</td>
<td>18%</td>
<td>11%</td>
</tr>
<tr>
<td>Stay out of the sun/Wear sunscreen</td>
<td>13%</td>
<td>9%</td>
</tr>
<tr>
<td>Environmental, Chemicals, Pollution, 2nd hand smoke, Pesticides,</td>
<td>23%</td>
<td>8%</td>
</tr>
<tr>
<td>Wear protective gear</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Healthy lifestyle, Positive attitude, Good state of mind, Safe</td>
<td>33%</td>
<td>6%</td>
</tr>
<tr>
<td>sex, Meditation, Yoga, Moderation, Do not have multiple partners</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Get screened for cancer/Get tested</td>
<td>25%</td>
<td>5%</td>
</tr>
<tr>
<td>Education, Well informed, Awareness, Books, Research</td>
<td>8%</td>
<td>4%</td>
</tr>
<tr>
<td>Reduce stress, Rest, Get enough sleep</td>
<td>8%</td>
<td>3%</td>
</tr>
<tr>
<td>Self exams, Body change awareness</td>
<td>15%</td>
<td>2%</td>
</tr>
<tr>
<td>Don't do drugs</td>
<td>3%</td>
<td>2%</td>
</tr>
<tr>
<td>Knowledge of family history, Good genes, Genetic testing</td>
<td>30%</td>
<td>1%</td>
</tr>
<tr>
<td>Limit exposure to carcinogens, Reduce toxins, Avoid causes of</td>
<td>8%</td>
<td>1%</td>
</tr>
<tr>
<td>cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduce weight, Maintain healthy weight</td>
<td>3%</td>
<td>1%</td>
</tr>
<tr>
<td>Religion, Prayer</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

*Mean number of ways mentioned* 4.03 2.31
Table 2. Responses to “What specific changes should people make in their eating habits to reduce their chances of getting cancer?”

<table>
<thead>
<tr>
<th>Proposed changes in eating habits</th>
<th>Interview responses</th>
<th>Population (HINTS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eat more vegetables</td>
<td>50%</td>
<td>51%</td>
</tr>
<tr>
<td>Eat less fat</td>
<td>20%</td>
<td>35%</td>
</tr>
<tr>
<td>Eat more fruits</td>
<td>35%</td>
<td>34%</td>
</tr>
<tr>
<td>Eat more fiber</td>
<td>8%</td>
<td>18%</td>
</tr>
<tr>
<td>Eat less red meat</td>
<td>10%</td>
<td>15%</td>
</tr>
<tr>
<td>Eat less fast food</td>
<td>5%</td>
<td>11%</td>
</tr>
<tr>
<td>Eat a balanced diet/All food groups/Follow food pyramid</td>
<td>10%</td>
<td>9%</td>
</tr>
<tr>
<td>Eat less/Healthy/Watch weight/Lose Weight</td>
<td>28%</td>
<td>8%</td>
</tr>
<tr>
<td>Less processing/chemicals/preservatives/additives</td>
<td>18%</td>
<td>8%</td>
</tr>
<tr>
<td>Take vitamin &amp; mineral supplements/herbal supplements/specific vitamin - food recommendations</td>
<td>8%</td>
<td>6%</td>
</tr>
<tr>
<td>Stop drinking alcohol/Reduce alcohol</td>
<td>20%</td>
<td>4%</td>
</tr>
<tr>
<td>Less sugar/sweets/sodas</td>
<td>5%</td>
<td>4%</td>
</tr>
<tr>
<td>Eat organic/natural/homegrown foods</td>
<td>10%</td>
<td>4%</td>
</tr>
<tr>
<td>Drink more water</td>
<td>5%</td>
<td>3%</td>
</tr>
<tr>
<td>Watch/lower cholesterol</td>
<td>0%</td>
<td>3%</td>
</tr>
<tr>
<td>Research foods/Read labels</td>
<td>0%</td>
<td>1%</td>
</tr>
<tr>
<td>Eat less salt/sodium</td>
<td>0%</td>
<td>1%</td>
</tr>
</tbody>
</table>

*Mean number of changes mentioned* 2.32 2.40
Table 3. Responses to “what kinds of tests should people get to find out whether they have cancer?”

<table>
<thead>
<tr>
<th>Tests</th>
<th>Interview responses</th>
<th>Population (HINTS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mammogram</td>
<td>50%</td>
<td>65%</td>
</tr>
<tr>
<td>Pap test</td>
<td>23%</td>
<td>40%</td>
</tr>
<tr>
<td>Colonoscopy / Sigmoidoscopy</td>
<td>15%</td>
<td>38%</td>
</tr>
<tr>
<td>PSA test</td>
<td>15%</td>
<td>33%</td>
</tr>
<tr>
<td>Clinical breast exam</td>
<td>20%</td>
<td>13%</td>
</tr>
<tr>
<td>Stool blood test / Fecal occult blood test</td>
<td>8%</td>
<td>12%</td>
</tr>
<tr>
<td>Blood test</td>
<td>40%</td>
<td>9%</td>
</tr>
<tr>
<td>X-ray</td>
<td>35%</td>
<td>6%</td>
</tr>
<tr>
<td>MRI / CT scan</td>
<td>32%</td>
<td>6%</td>
</tr>
<tr>
<td>Breast self-exam</td>
<td>18%</td>
<td>6%</td>
</tr>
<tr>
<td>Digital rectal exam</td>
<td>3%</td>
<td>3%</td>
</tr>
</tbody>
</table>

*Mean number of tests mentioned* 2.58 2.76
Table 4. Explanations of metaphors

<table>
<thead>
<tr>
<th>Metaphor</th>
<th>Mean Rating</th>
<th>Cancer is similar</th>
<th>Cancer is different</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accidents</td>
<td>2.80 (1.36)</td>
<td>Prevention is possible</td>
<td>Cancer has genetic factors</td>
</tr>
<tr>
<td>Contamination</td>
<td>2.73 (1.39)</td>
<td>Environmental exposure, abnormal cell growth</td>
<td>Cancer also has internal causes</td>
</tr>
<tr>
<td>Autoimmune Disease</td>
<td>2.69 (1.30)</td>
<td>Recurrence, no symptoms</td>
<td>Easier to treat, more localized, more suffering</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>2.66 (1.18)</td>
<td>Behavioral, environmental and genetic risk factors, progressive disease</td>
<td>More difficult to prevent or treat</td>
</tr>
<tr>
<td>Infectious Disease</td>
<td>2.59 (1.29)</td>
<td>Reoccurrence</td>
<td>Disease process</td>
</tr>
<tr>
<td>Parasitic Infection</td>
<td>2.20 (1.21)</td>
<td>Environmental exposure, disease process</td>
<td>More difficult to treat</td>
</tr>
<tr>
<td>Body Aging</td>
<td>1.96 (1.34)</td>
<td>Weaker body and more diseases with age</td>
<td>Affects all ages</td>
</tr>
<tr>
<td>Allergies</td>
<td>1.37 (.81)</td>
<td>Environmental exposure</td>
<td>More serious, more difficult to treat</td>
</tr>
</tbody>
</table>

Rating scale: 1 (very different from cancer) to 5 (very similar to cancer)