



David Ropeik

Why cancer is our most feared disease?

Q&A 25 April 2024

Q: Is there any evidence for success in curing cancer-phobia by taking into consideration the psychological issues?

A: THE ONLY WORK I CAME ACROSS IN MY RESEARCH WAS FINDINGS SUPPORTING THE EFFICACY OF INFORMED DECISION MAKING (IDM), WHICH BEARS ON THE PSYCHOLOGICAL RELEVANCE OF CONTROL/EMPOWERMENT, AND REGRET AVERSION. THE GIST OF WHAT I LEARNED WAS THAT GOOD IDM TOOLS DO HELP PEOPLE FEEL BETTER ABOUT THEIR CHOICES, BUT IT DOESN'T SEEM TO CHANGE WHAT THEY SAY WAS THEIR ORIGINAL CHOICE. I HAVE NOT SEEN MUCH RESEARCH TESTING MY OVERALL HYPOTHESIS DIRECTLY, IN SPECIFIC CHOICES ENVIRONMENTS (SCREENING, TREATMENT, AGE/GENDER/RACE/DEMOGRAPHICS)

Q: Hello and thank you all so VERY much for this session today. Could you please comment on the "Choosing Wisely" campaign that's lead by the American Board of Internal Medicine (ABIM)? I believe Choosing Wisely has been also been supported by the organization that published the monthly magazine Consumer Reports. Thank you again. Bravo.

A: THANK YOU. I CAN'T COMMENT SPECIFICALLY ON CHOOSING WISELY. I DON'T FEEL I KNOW IT WELL ENOUGH, THOUGH I DID SPEAK WITH DANIEL WOLFSON OF ABIM IN THE COURSE OF MY RESEARCH. I DID LEARN THAT IN GENERAL EFFORTS LIKE CHOOSING WISELY, TO EMPOWER MORE INFORMED CONSENT, DO HELP PEOPLE FEEL MORE COMFORTABLE WITH THEIR DECISION MAKING, THOUGH IT DOESN'T SEEM TO CHANGE THE DECISIONS THEY ORIGINALLY INTENDED TO MAKE. I WOULD ADD THAT IN CHECKING OUT DOZENS OF INFORMED DFECISION MAKING TOOLS (ACCESSIBLE ONLINE), I FOUND THAT ONLY A FEW ASKED QUESTIONS THAT HELPED PEOPLE THINK ABOUT THEIR CHOICES THROUGH THE RELEVANT EMOTIONAL LENSES, THINGS LIKE "HOW WOULD YOU FEEL IF YOU GOT A FALSE POSITIVE?" FRAMING THINGS THROUGH THE LENS OF FEELINGS WOULD, I THINK, BE PARTICULARLY HELPFUL.

ALSO, I FOUND MANY TOOLS THAT DID NOT INCLUDE INFORMATION OR QUESTIONS ABOUT SCREENING'S HARMS, ESPECIALLY THE POSSIBILITY OF OVERTREATMENT WITH SPECIFICS ABOUT SIDE EFFECTS. THAT WOULD BE RELEVANT TO PEOPLE;'S "OSS AVERSION" PSYCHOLOGY.

Q: Apologies if you discussed this already, but how do we deal with the companies that offer full-body scans for \$2.5k? Seems like they are adding to the cancer-phobia frenzy.

A: THERE ARE "INFLUENCERS" PROMOTING SUCH SCREENING. IT'S AN EASY BANDWAGON TO JUMP ON. ANYTHING PROMOTING MORE SCREENING IS. I STRONGLY BELIEVE THAT THE PREVENTING OVERDIAGNOSIS MOVEMENT NEEDS TO DEVELOP SUCH INFLUENCERS FOR ALL SORTS OF MESSAGING, INCLUDING THE MESSAGE THAT WHOLE-BODY SCANS ARE HIGHLY LIKELY TO FIND INCIDENTALOMAS AND SET OFF UNNECESSARILY HARMFUL MEDICAL CASCADES. SPEAKING AGAINST ANY TYPE OF CANCER SCREENING WILL BE DIFFICULT, HOWEVER, GIVEN OUR DEEP BELIEF IN THIS ONE TOOL BECAUSE IT FEELS LIKE EMPOWERMENT.

THESE INFLUENCERS SHOULD BE POPULAR FIGURES WHO HAVE EXPERIENCED THE HARMS OF WHOLE-BODY SCREENING OR OVERTREATMENT FOR OVERDIAGNOSED CANCERS. A DESIGNATED AND SMALL GROUP OF PRESTIGIOUS EXPERTS SHOULD BE DEVELOPED TO IDENTIFY THESE POTENTIAL INFLUENCERS (THROUGH INTERNET SEARCH AND CONVERSATION WITH PHYSICIANS) AND OFFER TO MEET WITH THEM TO INFORM THEM OF THE CONCERN ABOUT THE HARMS PEOPLE FACE FROM OVERSCREENING, AND DO THE BRAVE PUBLIC SERVICE OF ENLIGHTENING THE PUBLIC ABOUT THE ENORMOUS BUT LITTLE APPRECIATED THREAT OF OVERDIAGNOSIS, AND OVERTREATMENT FOR OVERDIAGNOSED CASES.

Q: How do we build informed consent for screening, when clinicians struggle to meet the needs of their patients in primary care?

A: FORGIVE ME IF THIS IS NAÏVE, BUT COMPENSATION FOR THE TIME IT TAKES HEALTH CARE PROVIDERS TO OFFER TRUE INFORMED CONSENT SEEMS TO BE A MAJOR OBSTACLE DOCTORS RAISE. IT SEEMS TO ME THAT INFORMED CONSENT HAS THE POTENTIAL TO SIGNIFICANTLY REDUCE NET MEDICAL COSTS, AND THAT MAKES IT APPEALING TO INSURERS. IF THAT HURDLE CAN BE OVERCOME, VIA MEETINGS WITH TOP HEALTH CARE INSURANCE EXECUTIVES, THERE WOULD BE PAYMENT FOR THE TIME IT TAKES FOR HEALTH CARE PROVIDERS TO PROVIDE TRUE INFORMED CONSENT. THE ARGUMENT WOULD BE THAT THE COST OF COMPENSATION IS MORE THAN MADE UP FOR BY THE SAVINGS IN AVOIDED UNNECESSARY MEDICINE. THEN INFORMED CONSENT COULD BE MADE A REQUIRED STEP WHEN PROVIDERS ARE TALKING TO PATIENTS ABOUT SCREENING CHOICES AND CERTAINLY ABOUT THEIR CHOICES REGARDING HOW TO RESPOND TO AN OVERDIAGNOSED CASE. (AS IT IS BY MEDICARE RE: LDCT SCREENING FOR LUNG CANCER! THE PRECENT IS SET.)

Q: Thank you for a very interesting talk. You argue that emotion and psychology are very important in explaining cancer fear. Is psychology and emotion equally important in demonstrating the risks and burdens of screening and treatment?

A: WE MAKE ALL OUR CHOICES THROUGH THE LENSES OF HOW WE FEEL. MY HYPOTHESIS IS THAT BY USING AN UNDERSTANDING OF THE SPECIFIC PSYCHOLOGICAL ELEMENTS MOST COMMONLY PERTINENT TO ANY SPECIFIC CHOICE, WHETHER SCREENING OR TREATMENT, INFORMED CONSENT TOOLS, PHYSICIAN COMMUNICATION TRAINING, AND OTHER APPROACHES CAN BUILD COMMUNICATION PROGRAMS THAT ARE MORE EFFECTIVE AT EMPOWERING CHOICES THAT HAVE FULLY ACCOUNTED FOR HOW PEOPLE FEEL ABOUT THE CHOICE, WHICH WILL IN TURN PRODUCE MORE THOROUGH CONSIDERATION OF THAT CHOICE.

Q: can you speak a bit longer about preventive surgery in women with BRCA mutations? I have the impression that women are actually forced to have prophylactic mastectomy and ovariectomy

that actually only save 3% of BRCA carriers....but DOCTORS are convinced these surgical procedures are much more effective.

A: HIGHER RISK CIRCUMSTANCES ARE BEYOND WHAT I FEEL I CAN KNOWLEDGEABLY TALK ABOUT. IN GENERAL I WOULD OFFER THAT THEY WILL INVOLVE UNIQUE EMOTIONS (PEOPLE WITH BRCA 1 AND 2 HAVE OFTEN LOST C LOSE RELATIVES TO CANCER) THAT STILL CAN BE UNDERSTOOD AND APPLIED TO MORE EFFECTIVE COMMUNICATION.

YOUR QUESTION, HOWEVER, RAISES A MORE PROFOUND CHALLENGE FOR THE OVERDIAGNOSIS MOVEMENT; HOW TO GET HEALTH CARE PROVIDERS IN IN ONCOLCOGY WHO HAVE DEVOTED THEMSELVES TO SAVING LIVES FROM CANCER TO GIVE FAIR RESPECT TO THE HARMS OF OVERSCREENING AND OVERTREATMENT, WHEN ALL THEY ARE FOCUSED ON IS SAVING ANY LIVES THEY CAN FROM CANCER.