What health policy makers need to know about mismatches between public perceptions of disease risk, prevalence and severity: A national survey

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ABSTRACT

OBJECTIVES

To assess people's perceptions of their personal risk, population prevalence and perceived severity in relation to three key health conditions (cancer, heart disease and hearing loss), gauge the size of any misperceptions, and identify correlates of such misperceptions.

DESIGN

Cross-sectional survey.

STUDY SAMPLE

10,401 adults representative of the UK population.

RESULTS

Clear majorities of people incorrectly believe that they are at greater personal risk of cancer (>75%), that cancer is more prevalent in the population (>50%) and that cancer is more disabling (>65%), than either heart disease or hearing loss. In turn, people consistently regard their personal risk of hearing loss, the population prevalence of hearing loss and the severity of hearing loss as lower than either cancer or heart disease. Multiple regression analyses showed inconsistent patterns of relationships between people's beliefs, sociodemographic characteristics and their health behaviours.

CONCLUSIONS

Accuracy in beliefs about cancer, heart disease and hearing loss is low, and the relationships between these beliefs, their potential antecedents and consequences are complex. Policy makers should ensure close adherence to evidence or risk making decisions that are costly both in financial terms and in terms of suboptimal population subjective well-being.

Introduction

The public play an increasingly important role in guiding health policy and setting the health research agenda. In England, for example, a special (£200M per annum) fund was set up in response to public demand (1, 2) for cancer treatments that had not been deemed costeffective by the National Institute for Health and Care Excellence (3). Similarly, numerous governments worldwide are experiencing renewed public resistance to established vaccines (4). Enduring mismatches between public perceptions of the prevalence of- and perceived personal risks associated with- disease therefore potentially undermine the role of evidencebased decision making in public health policy (1). The aim of the present research was to quantify the scale of public misperceptions about three key chronic conditions and to identify psychosocial correlates of these misperceptions. The present study focuses on three main conditions: cancer, heart disease and hearing loss. We have chosen cancer and heart disease to see whether US population misperceptions about the prevalence and personal risk of these conditions are generalisable (5). We have added hearing loss as a third condition because it is both more prevalent and exerts greater disease burden in terms of years lived with the condition than either cancer or heart disease (6), and because there is a substantial gap between perceptions of having a hearing loss and seeking help (7).

In the United States, a large minority of US citizens (42.8%) believe that cancer is more prevalent than heart disease (5), yet in 2014, 20.3M adults were diagnosed with cancer whereas 27.6M adults were diagnosed with heart disease (8). At the same time, a majority of US citizens (78.5%) perceive that their personal risk of cancer exceeds or is the same as their personal risk of heart disease (5). With 2.5 million people in the UK living with cancer (9), alongside 7.4 million living with heart disease (10) and 11 million living with hearing loss (11), such mismatches in public perceptions are important because they could undermine attempts to focus resources on the areas that will exert the largest influence on improving subjective well-being, the key index of government policy-making worldwide (12) and the thing that matters most to people (13) in three key respects. First, if the misperceptions about the prevalence of cancer and people's perceived personal risk of cancer as opposed to heart disease translate to the UK population, then it could impact on early detection of disease and have serious implications for healthcare budgets. Second, underestimating the risks and harms of hearing loss may divert resources away from hearing health research and practice that may exert proportionately greater positive effects on subjective well-being than equivalent spending on cancer or heart disease. A third possible consequence of such misperceptions is that underestimating one's personal risk is liable to undermine the personal

health protective behaviours that reduce ill health (5). The question then arises as to what might be driving these misperceptions, and how they might be addressed. The literature is limited in this regard, but Scheideler and colleagues (5) identify socioeconomic status, age, gender, health behaviours (e.g., not smoking, eating healthily) as potential correlates of misperceptions, but with sample sizes smaller than N = 2000, they may not have been sufficiently powered to identify key correlates even if they existed.

For the first time, the present study aims to assess the level of misperceptions of personal risk and population prevalence of key health conditions in a large sample that is representative of the UK population. It is hypothesized that people will: (a) underestimate their personal risk of hearing loss, relative to cancer and heart disease, (b) underestimate the population prevalence of hearing loss, relative to cancer and heart disease, and (c) socioeconomic status, age, gender and health behaviours will be associated with perceptions of risk and prevalence.

Method

Design and Procedure

The study design was cross-sectional and administered as part of a larger online survey (14). YouGov, a market research company, recruited a sample of 10,401 UK residents aged 18+ in March 2019 from their existing database. A sample of adults designed to be representative of the UK population was invited to take part in an online questionnaire and were incentivised in accordance with YouGov's points system, whereby respondents accumulate points for taking part in online surveys. The completion rate was 90.6% and the data were sent securely to the research team for analysis. Ethical approval was obtained from a University Research Ethics Committee (ref: 2019-5769-9246) and participants gave informed consent at the beginning of the survey. A questionnaire, which included measures of sociodemographic characteristics; personal perceptions and population estimates of cancer heart disease and hearing loss; and relevant health behaviours and was designed specifically for the purposes of the present study, was embedded in a wider online anonymous survey.

Materials

Personal perceptions. Personal perceptions of risk were measured in the same way as Scheideler et al. (5) to facilitate direct comparison with their findings. Thus, perceived absolute risk of cancer, heart disease, and hearing loss were assessed on three independent five-point scales (very unlikely[1]-very likely[5]) with: "How likely are you to get cancer /

heart disease / hearing loss in your lifetime?". Subtracting the perceived absolute risk of cancer, heart disease, and hearing loss scores from one another produced relative personal risk perception scores. Scores ranged from -4 to +4, with higher scores representing beliefs that: (a) personal risk of cancer exceeded heart disease risk, (b) personal risk of cancer exceeded hearing loss risk, and (c) personal risk of heart disease exceeded hearing loss risk.

Population estimates. Consistent with Scheideler et al. (5), population prevalence estimates of cancer, heart disease, and hearing loss were measured on four-point scales (strongly disagree[1]-strongly agree[4]) with: "In adults, cancer is more common than heart disease," "In adults, cancer is more common than hearing loss," and "In adults, heart disease is more common than hearing loss." In addition to the Scheideler et al. (5) measures, population severity estimates of cancer, heart disease, and hearing loss were measured on four-point scales (strongly disagree[1]-strongly agree[4]) with: "In adults, cancer is more disabling than heart disease," "In adults, cancer is more disabling than hearing loss," and "In adults, heart disease is more disabling than hearing loss."

Health behaviours. Four health behaviours, related to increased risks of cancer, heart disease and hearing loss (15-17) were assessed using standard scales. Cigarette smoking was assessed using the UK Office for National Statistics' (18) measures, which asks: "Do you smoke cigarettes at all nowadays? Yes/No". Smoking status was coded as 1 = smoker, 0 = non-smoker.

Alcohol consumption was assessed using the UK Office for National Statistics' (19) standard measure, which asks participants: "How often have you had an alcoholic drink of any kind during the last 12 months?" to which people respond on an eight-point scale labelled, "Almost every day," "5 or 6 times a week," "3 or 4 days a week," "Once or twice a week," "Once or twice a month," "Once every couple of months," "Once or twice a year," or "Not at all in last 12 months." Higher values indicate greater alcohol consumption.

Unhealthy eating was assessed by adapting the emotional eating subscale of the Dutch Eating Behaviour Questionnaire (20), high scores on which are associated with problematic eating patterns including weight gain and psychiatric disorders (21). The most representative item based on a recent principal components analysis (22) in a community sample was used to minimize participant burden: "How often did you eat because you were bored or restless during the last 12 months?" and the response options were changed from never, seldom, sometimes, often, and very often to match the alcohol consumption measure, namely: "Almost every day," "5 or 6 times a week," "3 or 4 days a week," "Once or twice a week," "Once or twice a month," "Once every couple of months," "Once or twice a year," or "Not at all in last 12 months." Higher values indicate greater unhealthy food consumption.

Sedentariness was assessed using the relevant item from the short version of the International Physical Activity Questionnaire (23), which defines sedentariness as: "... the time you spent sitting during the last 7 days. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television." Participants were asked: "During the last 7 days, how much time did you spend sitting on a typical working day? hours per day minutes per day / I don't work" and "In the last 7 days, how much time did you spend sitting on a typical non-working day? _____ hours per day _____ minutes per day." Higher values indicate greater sedentariness.

Patient and Public Involvement

One hundred and fifty four members of the public were consulted about the purpose of the study and tried out some of the key questionnaire items at two public engagement events held in Manchester in April and June 2018. The consultation revealed broad approval for the purposes of the study and some minor amendments in the wording of the questionnaire items. We will work with the NIHR Manchester Biomedical Research Centre's patient and public involvement panel to produce accessible summaries of the work.

Analyses

Proportions were computed to illustrate prevailing perceptions of personal risk and population prevalence. Personal risk perceptions and perceived population prevalence were entered as "dependent" variables in multiple regressions to examine associations between population views and health behaviours, and sociodemographic factors.

Results

Participant Characteristics

Consistent with the sampling frame, the sample (N = 10,401) was representative of the UK population

(https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/population estimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland). Most participants were white (n = 9,764, 93.9%) and half were women (n = 5,305, 51.0%)

and roughly evenly split between people in non-manual (n = 5,367,51.6%) and manual occupations (n = 5,034, 48.4%). Mean age was 47.41 years (SD = 1.48).

Personal Risk Perceptions

Table 1 presents the data as means and standard deviations, but consistent with the aims of the study to inform policy makers, the data are interpreted here in terms of proportions of populations. Almost one-third of the sample (30.5%) believed their personal risk cancer exceeded their personal risk of heart disease and 54.1% reported no difference between their cancer and heart disease risk. Just 15.3% of the sample correctly judged their personal risk of heart disease exceeded that of their personal risk of cancer. A similar pattern of findings emerged when cancer and heart disease were contrasted with personal risk of hearing loss (Table 1). Thus, greater than one-third of the sample (37.9%) believed their personal risk of cancer exceeded their personal risk of hearing loss; 39.8% reported no difference between their cancer and hearing loss risk; and just 22.4% correctly judged their personal risk of hearing loss exceeded that of their personal risk of cancer. More people (27.0%) correctly believed that their personal risk of hearing loss exceeded their personal risk of heart disease, but 73.0% believed that their personal risk of heart disease was either the same as- or lower than- their risk of hearing loss.

Population Prevalence and Severity Perceptions

When people were asked to judge the population prevalence of cancer, heart disease and hearing loss (Table 1), majorities of participants agreed or agreed strongly that cancer was more common than heart disease (58.1%) and hearing loss (53.1%), and that heart disease was more common than hearing loss (55.7%). When people were asked about the severity of these conditions, they again agreed or strongly agreed that cancer was more disabling than heart disease (67.2%) and hearing loss (79.6%), and that heart disease was more disabling than hearing loss (68.3%). Thus, in judgments of prevalence and severity, only small numbers of people in our representative sample gave responses that were close to the epidemiological data.

Correlates

Correlations between personal risk perceptions, population prevalence estimates, severity perceptions and health behaviours were low and none exceeded Cohen's (24) benchmark of r = .30 for a "medium-sized" effect. Thus, people's perceptions of their personal risks are

relatively independent of their estimates of population prevalences and their perceptions of the severity of these conditions, and justifies considering associations with sociodemographic factors and health behaviours separately in the subsequent analyses.

Associations With Sociodemographic Factors and Health Behaviours

Personal risk perceptions. Those who thought their personal risk of cancer exceeded their risk of heart disease were more likely to be women, younger, had lower socioeconomic status, a white ethnic background, consumed more alcohol, ate more unhealthily but were less likely to be sedentary (Table 2). Smoking status was unrelated to the belief that personal risk of cancer exceeds their risk of heart disease. Those who thought their risk of cancer exceeded their risk of hearing loss were more likely to be women, younger, people with a white ethnic background, smokers, and people who ate unhealthily. Socioeconomic status, alcohol consumption and sedentariness were unrelated to the belief that personal risk of cancer exceeds the risk of heart disease. Those who thought their risk of heart disease exceeded their risk of hearing loss were more likely to work in manual occupations, smoke, and eat unhealthily. Gender, age, ethnicity and sedentariness were unrelated to people's belief that personal risk of heart disease exceeds their risk of hearing loss.

Population prevalence estimates. Those who thought the population prevalence of cancer exceeds heart disease prevalence were more likely to be women, younger, in manual occupations, have a white ethnic background, consume more alcohol, and eat more unhealthily (Table 2). Smoking status and sedentariness were unrelated to the belief that population prevalence of cancer exceeds heart disease prevalence. Those who thought the prevalence of cancer exceeds hearing loss prevalence were more likely to be women, younger, have a white ethnic background, have a manual occupation, drink less alcohol, and eat unhealthily. Smoking status and sedentariness were unrelated to the belief that the population prevalence of cancer exceeds hearing loss prevalence. Those who thought the prevalence of heart disease exceeds hearing loss prevalence were more likely to be women, have a manual occupation, a Black, Asian or Minority Ethnic background, smokers, consumers of fewer units of alcohol, and people who ate unhealthily. Age and sedentariness were unrelated to the belief that population prevalence of heart disease exceeds hearing loss prevalence.

Severity perceptions. Those who thought that the disability from cancer exceeds heart disease were more likely to be younger, have a manual occupation, were smokers and eating unhealthily (Table 2). Gender, ethnicity, alcohol consumption and sedentariness were unrelated to beliefs that disability from cancer exceeds heart disease disability. Those who thought that the disability from cancer exceeds hearing disability were more likely to be men, older, have a manual occupation, white ethnic background, consume more alcohol, and eat unhealthily. Smoking status and sedentariness were unrelated to beliefs that the disability from cancer exceeds hearing loss disability. Among people who thought that the disability from heart disease exceeds hearing disability were more likely to be men, older people, people in a manual occupations, and smokers. Ethnic background, alcohol consumption, sedentariness and unhealthy eating were unrelated to beliefs that disability from heart disease exceeds hearing disability.

Discussion

Principal Findings

The public perceive themselves to be at much greater risk of cancer and that cancer is much more prevalent and disabling than either heart disease or hearing loss, despite the fact that both heart disease and hearing loss are more prevalent and disabling.

Strengths and limitations

The sample was large and representative, but the cross-sectional design means that causality cannot be inferred. Although limited in its own respects our ability to compare UK data directly with US data (5) is one positive aspect, it meant that our measure of relative personal risk was indirect (i.e., operationalized as a difference score) rather than direct, and differed from our measures of prevalence and severity. Nevertheless, prevalence and severity perceptions were no more closely related than were personal risk perceptions, implying that the form the questions took may not have been an issue. We did not ask whether participants or their families actually suffered cancer, heart disease or hearing loss and in future research it would be valuable to examine ways in which this affects the findings.

Previous studies

Inaccuracies in perceptions of personal risk, population prevalence and disability, associated with cancer and heart disease were more marked in our UK sample than in US data (5). The implications are that the skew in terms of funding services and research in the UK are more extreme than those in the US (5).

Implications

It is difficult to untangle precisely what the UK government spends per year on cancer, heart disease and hearing loss, but figures on charitable donations may well be reflective of broader societal trends. In 2017-18, Cancer Research UK was the leading charity in terms of funds raised with £443,200,000 and the British Heart Foundation was second with £295,900,000 (25). There are numerous other cancer-related charities in the top 100, but only one hearing loss charity (National Deaf Children's Society is 74th [£23,400,000], below the Donkey Sanctuary in 52nd [£33,800,000]). Changing or formulating policy in spite of public perceptions of hearing loss might provide "quick wins" in terms of investing in hearing health to maximize subjective well-being (12) through reducing social isolation, loneliness, depression and, potentially, dementia (26).

Given that people's perceptions of risk, prevalence and severity are only loosely correlated with one another and the predictors of people's perceptions are complex, policy makers either need to adjust misperceptions, or policy decisions based on the evidence will need to be prioritised consistently over public perceptions (1, 2). One possible compromise is that policy makers make explicit the relative weights of evidence versus public opinion in their decision making.

Future research

Ultimately the goal of this research is to develop interventions that will change the behaviour of the population to improve health outcomes. Further in-depth work is required to understand further the myths and misperceptions of the public in relation to personal risks, population prevalences and severity judgments, and how to overcome them, because reasoned reflections on risk and severity are just one of many possible routes via which people's behaviour changes (27-29). It would also be valuable to track longitudinally changes in public perceptions of key public health issues and to examine whether it is the salience of mortality in cancer and heart disease messaging that distracts the public from the actual burden associated with hearing loss (6).

CONCLUSIONS

Public accuracy in beliefs about cancer, heart disease and hearing loss is low, and the relationships between these beliefs, their potential antecedents and consequences are complex. Policy makers should ensure close adherence to evidence or risk making decisions that are costly both in financial terms and in terms of suboptimal population subjective well-being. Increasing transparency in the relative weightings of evidence versus public opinion might be one way forward in better explaining public health policy decisions.

Abbreviations:

NIHR: National Institute for Health Research

UK: United Kingdom

US: United States

DECLARATIONS

Ethics approval and consent to participate: Ethical approval was obtained from a University Research Ethics Committee (ref: 2019-5769-9246) and participants gave informed consent at the beginning of the survey.

Consent for publication: No patient-identifying personal information was collected.

Availability of data and materials: Data and materials on reasonable request will be available one year following publication from CJA.

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Table 1
Personal Risk Perceptions and Population Prevalence Estimates of the Sample

Variable	%	M	SD
Personal Risk			
Cancer exceeds heart disease		0.21	0.91
Cancer exceeds hearing loss		0.26	1.18
Heart disease exceeds hearing loss		0.04	1.16
Population Prevalence			
Cancer exceeds heart disease		2.68	0.78
Cancer exceeds hearing loss		2.60	0.89
Heart disease exceeds hearing loss		2.64	0.80
Severity			
Cancer exceeds heart disease		2.83	0.75
Cancer exceeds hearing loss		3.15	0.80
Heart disease exceeds hearing loss		2.89	0.81

Table 2
Statistically Significant Associations With Sociodemographic Factors and Health Behaviours

Variable	В	SE	95% CI	p
Criterion: Risk of Cancer				
Exceeds Heart Disease Risk				
Gender	.119	.019	.082, .156	< .001
Age	010	.001	011,008	< .001
Social Grade	066	.019	102,029	< .001
Ethnicity	227	.038	301,153	< .001
Alcohol Consumption	.021	.005	.012, .031	< .001
Unhealthy Eating	010	.004	018,002	< .05
Sedentariness	.001	.001	011,008	< .001
Criterion: Risk of Cancer				
Exceeds Hearing Loss Risk				
Gender	.119	.025	.070, .167	< .001
Age	009	.001	011,008	< .001
Ethnicity	181	.050	278,083	< .001
Smoking	.270	.035	.202, .339	< .001
Unhealthy Eating	.013	.006	.002, .023	< .05
Criterion: Risk of Heart				
Disease Exceeds Hearing				
Loss Risk				
Social Grade	.050	.024	.003, .098	.001
Smoking	.276	.034	.208, .343	.001
Unhealthy Eating	.024	.005	.013, .035	.001
Criterion: Prevalence of				
Cancer Exceeds Heart				
Disease Prevalence				
Gender	.077	.016	.047, .107	< .001
Age	005	.001	006,004	< .001
Social Grade	.041	.015	.010, .071	< .01
Ethnicity	114	.032	178,051	< .001
Alcohol Consumption	.008	.003	.013, .027	< .05

Unhealthy Eating	.020	.003	.013, .027	< .01
Criterion: Prevalence of				
Cancer Exceeds Hearing Loss				
Prevalence				
Gender	.078	.018	.043, .112	< .001
Age	005	.001	006,004	< .001
Ethnicity	181	.050	278,083	< .001
Social Grade	.138	.018	.104, .172	< .001
Alcohol Consumption	011	.005	020,002	< .05
Unhealthy Eating	.020	.004	.012, .027	< . 001
Criterion: Prevalence of				
Heart Disease Exceeds				
Hearing Loss Prevalence				
Gender	.039	.016	.008, .071	< .05
Social Grade	.133	.016	.102, .164	< .001
Ethnicity	.087	.034	.022, .153	< .01
Smoking	.082	.023	.037, .127	< .001
Alcohol Consumption	017	.004	026,009	< .001
Unhealthy Eating	.020	.004	.013, .027	< .001
Criterion: Disability From				
Cancer Exceeds Heart				
Disease Disability				
Age	003	.001	004,002	< .001
Social Grade	.035	.015	.006, .065	< .05
Smoking	.060	.022	.017, .102	< .01
Unhealthy Eating	.008	.003	.001, .014	< .05
Criterion: Disability From				
Cancer Exceeds Hearing Loss				
Disability				
Gender	056	.016	087,025	< .001
Age	.004	.001	.003, .004	< .001
Social Grade	.042	.016	.011, .073	< .01
Ethnicity	166	.033	232,101	< .001

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Alcohol Consumption	.012	.004	.004, .020	< .01
Unhealthy Eating	.008	.004	.001, .015	< .05
Criterion: Disability From				
Heart Disease Exceeds				
Hearing Loss Disability				
Gender	155	.016	186,124	< .001
Age	.010	.001	.009, .011	< .001
Social Grade	.041	.016	.010, .072	< .01
Smoking	.056	.023	.011, .101	< .05