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Overcoming the knowledge–behavior gap: The effect of evidence-based HPV vaccination leaflets on understanding, intention, and actual vaccination decision

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ABSTRACT

Objective: Informed decision making requires transparent and evidence-based (=balanced) information on the potential benefit and harms of medical preventions. An analysis of German HPV vaccination leaflets revealed, however, that none met the standards of balanced risk communication.
Methods: We surveyed a sample of 225 girl–parent pairs in a before–after design on the effects of balanced and unbalanced risk communication on participants' knowledge about cervical cancer and the HPV vaccination, their perceived risk, their intention to have the vaccine, and their actual vaccination decision.
Results: The balanced leaflet increased the number of participants who were correctly informed about cervical cancer and the HPV vaccine by 33 to 66 absolute percentage points. In contrast, the unbalanced leaflet decreased the number of participants who were correctly informed about these facts by 0 to 18 absolute percentage points. Whereas the actual uptake of the HPV vaccination 14 months after the initial study did not differ between the two groups (22% balanced leaflet vs. 23% unbalanced leaflet; $p = .93$, $r = .01$), the originally stated intention to have the vaccine reliably predicted the actual vaccination decision for the balanced leaflet group only (concordance between intention and actual uptake: 97% in the balanced leaflet group, $r_s = .92$, $p = .00$; 60% in the unbalanced leaflet group, $r_s = .37$, $p = .08$).
Conclusion: In contrast to a unbalanced leaflet, a balanced leaflet increased people's knowledge of the HPV vaccination, improved perceived risk judgments, and led to an actual vaccination uptake, which first was robustly predicted by people's intention and second did not differ from the uptake in the unbalanced leaflet group. These findings suggest that balanced reporting about HPV vaccination increases informed decisions about whether to be vaccinated and does not undermine actual uptake.

1. Introduction

Unbalanced reporting is a recognized issue in the communication of medical facts [1,2]. It ranges from incomplete and nontransparent information (e.g., omitting potential harms, reporting relative risk instead of absolute risk reduction/increase) to active persuasion [3–8]. As the "pill scare" in the United Kingdom documents, misinforming patients through unbalanced reporting can have dramatic consequences. In 1995, after the U.K. Committee on Safety for Medicine stated that the risk of thromboembolism doubles when taking the third generation of the oral contraceptive pill compared to the second generation, many women stopped taking the pill [9]. Results were unwanted pregnancies and an estimated increase of 13,000 abortions in the following year [10]. The message of "double the risk", which scared so many women, was in fact based on the following absolute numbers: 1 in 7000 women who took the second generation pill suffered from thromboembolism compared to 2 in 7000 who took the third generation pill [1]. If the U.K. Committee had used these absolute numbers to communicate the risk increase, many women might have reacted differently and been saved from unwanted pregnancies and abortions.

Although ethical policies in Germany and elsewhere increasingly stipulate that participation in medical prevention should reflect informed choice, particularly because prevention targets healthy people [11], this has not yet been translated into practice.

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For instance, a recent study [3] published in *Vaccine* revealed unbalanced reporting in the German coverage of the human papillomavirus (HPV) vaccination, which has been recommended and covered by German health authorities since March 2007 for girls aged 12–17 years. To determine what counts as unbalanced and balanced reporting, the authors of that study identified the following criteria as standards of good risk communication [3]:

(1) *Completeness* (baseline risk of cervical cancer, benefit and harms of vaccination)
(2) *Transparency* (presentation of all risk information in absolute numbers, not relative numbers; provision of a reference class)
(3) *Correctness* (evidence-based information)

It and a further study [3,4] documented that both leaflets from German health agencies and the media provide incomplete information about the risk of cervical cancer and the vaccination's effectiveness and use nontransparent statistics to communicate the benefit and harms of vaccination. None of the studied leaflets provided correct and transparent numbers on the effectiveness of HPV vaccination, and more than 60% did not mention any harms at all related to the vaccine [4]. Until now, it had not been studied whether and how unbalanced reporting on HPV vaccination affects the target persons.

2. Aims of the study

The current study sought to learn how balanced versus unbalanced information about HPV vaccination influences (1) girls' and parents' knowledge of the risk of cervical cancer and the effectiveness of the HPV vaccine (both being the basis for informed decisions), (2) their perceived risk of developing cervical cancer without having the HPV vaccine, (3) the intention to have the vaccine, (4) the actual vaccination decision, and (5) the phenomenon of the "knowledge–behavior gap".

In accordance with results from current research, we hypothesized that balanced health information would increase people's knowledge [12–14] about the risk of the disease and the effectiveness of the vaccine, reduce people's perceived risk of getting cervical cancer without having the HPV vaccine, and reduce their intention to have the HPV vaccine [15–17]. Little is known, however, about how balanced information influences the actual vaccination decision. In a study by Steckelberg and colleagues [18] investigating the effect of evidence-based risk information about colorectal cancer screening on people's knowledge and screening decision, the authors found increased knowledge about the efectiveness of the screening but no undermining effect on people's screening intentions or actual screening decision. Previous research has already discovered incongruities between people's knowledge and their actual health behavior (e.g., [19,20]). Terms such as the "knowledge–behavior gap" have been coined for this phenomenon, where medical education interventions were found to improve people's knowledge without altering their behavior (e.g., [21,22]). To the best of our knowledge, however, none of the studies on the knowledge–behavior gap accounted for the fact that information on the same medical topic can be presented in different formats, which may affect the phenomenon differently. Our study was designed to enable examination of whether balanced or unbalanced information indeed affect the correspondence of knowledge and behavior differently. If participants' knowledge and their actual vaccination decisions were found to be uncorrelated under each condition, this would suggest that other mechanisms (e.g., following the "trust-your-doctor" heuristic [23]) than the information format influence vaccination decisions. If participants' knowledge and their actual vaccination decisions were found to be correlated in one or the other setting, this would suggest that the knowledge–behavior gap depends on how information is presented.

3. Method

3.1. Participants

The focus of the study was on parents *and* girls. Because we wanted to investigate participants' views before exposure to the HPV vaccination, we recruited all girls from 6th-grade classes at German secondary schools at the beginning of the school year. To ensure socioeconomic diversity of the sample, we chose a convenience sample of 16 secondary schools from eight districts in Berlin. All participants who showed interest in the study gave their consent; for the girls we requested written consent from one of their parents. Participation rates per school varied between 57% and 85%. Altogether, we collected 225 complete girl–parent data sets (balanced leaflet: $n = 122$, unbalanced leaflet: $n = 103$). Within the parent sample, 95% of the 225 participants were mothers, the mean age was 41.4 (*SD*: 5.3), and 91% had at least a high-school degree.

4. Material

Leaflets. In the unbalanced leaflet group, participants received a leaflet from a major German cancer organization (*Deutsche Krebshilfe*) that did not meet the criteria of balanced risk communication as outlined above (see Table 1). In the balanced leaflet group, participants received a leaflet that was based on the facts box for Gardasil (see Table 2), recently published in *Vaccine* [3] and in *Bundesgesundheitsblatt* [4]. The balanced and unbalanced leaflets (in German) are accessible via http://www.harding-center.com/HPV/study_materials. Tables 1 and 2 describe the content of each leaflet with respect to each of the criteria outlined earlier as necessary for balanced risk communication.

4.1. Survey procedure

Our study was conducted between January and March 2010 in Germany. Girls were visited in their classrooms on a predetermined date; parents received their study materials via their daughters and completed the study alone. After the girls were explained the purpose and procedure of the study, they were randomly assigned to either the balanced leaflet group or the unbalanced leaflet group. Each girl was then asked to complete the first part (before leaflet) of the survey, subsequently received the respective leaflet to read, and then worked through the second part (after leaflet) of the survey. After completion, each girl was given an envelope for their parent that contained instructions for the study, a survey, and a leaflet. Parents were assigned to the same group as their daughter (balanced leaflet or unbalanced leaflet). We asked the girls to return the completed materials from their parents to school within 3 days. For each complete data set (survey of girl and parent), participants were given a 15-euro Amazon voucher. Seventy-two percent of all contacted parents returned their survey, and 59% of them agreed to be recontacted about a year later for the second part of the study investigating the actual HPV vaccination decision.

4.2. Survey

The survey took the following outcome measures: knowledge of cervical cancer; knowledge of the purpose, benefit, and harms

Table 1
Information provided in the leaflet from one of Germany's Major Cancer Organizations, Deutsche Krebshilfe, Chosen as the Unbalanced Leaflet Condition.

Criteria for balanced risk communication	What does the leaflet report?	What is unbalanced about it?
Completeness		
Base risk	6700 women are diagnosed every year 1800 women die of cervical cancer per year	Is mute about the references classes for incidence and mortality (out of 43 million German women = incidence: 0.01%, mortality: 0.004%)
Benefit	Vaccine is 98% effective for HPV types 16 and 18, which cause 70% of cervical cancer	Suggests that the vaccine would prevent almost 70% of all cervical cancers. Approval studies demonstrated an effectiveness of 29% at most, which is not reported
Harms	Redness at injection site	Does not mention any other harms and provides no numerical information
Transparency	–	Provides neither absolute numbers nor the reference class
Correctness/Evidence-based information	–	Does not mention the evidence from the approval studies Future I or II Does not report that outcome measures were surrogate markers, not actual cervical cancer

of HPV vaccination; perceived risk of getting cervical cancer without the HPV vaccine; intention to have the HPV vaccine; and actual decision on HPV vaccination. To investigate each outcome, we filed the following questions: How many women out of 100,000 develop cervical cancer every year? (*up to 10, 100, 1000, more than 1000, I don't know*); How many women out of 100,000 die of cervical cancer every year? (*up to 10, 100, 1000, more than 1000, I don't know); What has the HPV vaccine been shown to prevent? (precancerous forms of cervical cancer, cervical cancer, I don't know); Out of 100,000 women, how many deaths from cervical cancer could be prevented by HPV vaccination? (1, up to 10, 100, 1000, I don't know);* Tick all of the following listed harms you think are associated with HPV vaccination (*infertility, issues at the injection site, e.g.; swelling, redness, pain, seasonal allergies, unspecific pain or problems with the joints (arthritis), breathing trouble/shortness of breath, hallucinations, none of these*); **How** risky do you think it is to develop cervical cancer without having the HPV vaccine? (*not risky, not very risky, somewhat risky, very risky, highly risky*); Do you think that you would like to have the HPV vaccine? (*yes, no, I am not sure*); Has your daughter been vaccinated for HPV in the meantime? (*yes, no*). The exact formulations of the questions can be seen in the Appendix.

4.3. Analysis

Data were stored and analyzed using SPSS (version 18). If a response was lacking for any outcome, it was coded as a missing response. Because our outcome measures yielded ordinal data, which are not normally distributed, we used nonparametric tests. All between-subject comparisons were analyzed with the *Mann–Whitney U* test, and all within-subject comparisons were analyzed with the *Wilcoxon rank-sum* test. The resulting *z*-values of these nonparametric tests were converted into the effect size measure *r*. The concordance between people's vaccination intention and their actual vaccination decision was analyzed with Spearman's correlation. To transparently depict the effect that the two formats of risk communication would have on the outcomes, we further calculated the change from "before leaflet" to "after leaflet" in absolute percentage points.

5. Results

5.1. Knowledge of cervical carcinoma

The majority of the participants largely overestimated or did not know the incidence and mortality of cervical carcinoma before reading the leaflet. Sixty-four percent of the girls and 27% of the parents thought that at least 1000 or more women in 100,000 were diagnosed with cervical carcinoma every year in Germany; 16% of the girls and 30% of the parents said that they did not know how many. Similarly, 61% of the girls and 36% of the parents believed that women's risk of dying from cervical cancer was at least 100 in 100,000 or more. Table 3 shows how reading the leaflets changed participants' knowledge.

For instance, reading the balanced leaflet increased the number of girls who arrived at a correct estimate of the incidence by 66% points and decreased the number of girls who overestimated the

Table 2
Information provided in the leaflet developed for the balanced leaflet condition.

Criteria for balanced risk communication	What does the leaflet report?	What is balanced about it?
Completeness		
Base risk	15 women in 100,000 are diagnosed per year 3 women in 100,000 die of cervical cancer per year	Provides the base rate and the reference class
Benefit	Incidence reduction: from 15 to 11 in 100,000 per year (=4 less in 100,000) Mortality: from 3 to 2 in 100,000 per year (=one less in 100,000)	Provides the base rate and the absolute risk reduction
Harms	Very common (>10,000 in 100,000): fever, redness, pain, and swelling at the injection site Common (1000–10,000 in 100,000): seasonal allergies Rare (100–1000 in 100,000): unspecific arthritis	Provides numerical information on the most common harms
Transparency	Yes	Each section provides information about the base rate, reference class, and risk reduction/increase. Information is provided as absolute numbers and the same reference class of 100,000 is used for all benefits and harms
Correctness/Evidence-based information	Yes	Numbers are based on the approval studies, and on data from the German Federal Agency of Statistics and the German Standing Vaccination Committee (*STIKO*)

Table 3
Changes (in absolute percentage points) in knowledge about the incidence and mortality of cervical cancer from before to after reading the leaflet.

		Change in knowledge about incidence of cervical carcinoma		*Effect size (95% CI)*	Change in knowledge about mortality of cervical carcinoma		*Effect size (95% CI)*
		Correct estimates	Overestimates		Correct estimates	Overestimates	
Girls	Unbalanced leaflet*	25–12.6% (n = 103)	+24.3% (n = 103)	r = –.11 (–.30; .09)	–17.9% (n = 102)	+26.8% (n = 102)	r = –.21 (–.39; –02)
	Balanced leaflet	+65.7% (n = 118)	–54.1% (n = 118)	r = –.74 (–.81; – 65)	+56.8% (n = 119)	–46% (n = 119)	r = –.67 (–.76; – 56)
Parent	Unbalanced leaflet*	–1.2% (n = 102)	+9.4% (n = 102)	r = .00 (–.19; .19)	–1% (n = 102)	+14.1% (n = 102)	r = –.06 (–.25; + 13)
	Balanced leaflet	+32.6% (n = 119)	–15.5% (n = 119)	r = –.50 (–.62; –.35)	+33.4% (n = 121)	–11.2% (n = 121)	r = –.53 (–.65; –.39)

* Colored boxes highlight decreases in knowledge about the incidence and mortality of cervical carcinoma after reading the leaflet.

likelihood of dying from cervical cancer by 46% points. In contrast, reading the unbalanced leaflet decreased the number of girls who arrived at a correct estimate of the incidence by 13% points and increased the number of girls who overestimated the likelihood of dying of cervical cancer by 27% points.

5.2. Knowledge of the benefit and harms of HPV vaccination

Furthermore, most participants did not know what the HPV vaccine has been shown to prevent (precancerous lesions), nor did they know how many deaths from cervical cancer could potentially be prevented by having the vaccine (1 in 100,000). For instance, 62% of the girls and 63% of the parents stated that having the HPV vaccine would certainly prevent cervical cancer, and 59% of all participants assumed that having the vaccine would prevent 100 and more deaths in 100,000.

The effect of each leaflet on participants' HPV vaccination-related knowledge is shown in Table 4. Both leaflets increased the number of girls who now correctly understood that the vaccination has been shown to prevent precancerous lesions, whereas only the balanced leaflet increased the number of parents who understood this. The balanced leaflet further improved participants' knowledge about the benefit of the vaccination (mortality reduction): 49% more girls and 48% more parents now gave a correct estimate of the vaccine's efficacy. By contrast, participants in the unbalanced leaflet group, showed a decrease of knowledge and an increase in overestimation: 22% more girls and 10% more parents overestimated the effect of the vaccination on cervical cancer mortality after having read the unbalanced leaflet (see Table 4).

To learn about the impact of the leaflets on participants' knowledge of the HPV vaccination harms, we gave participants a list of possible harms after reading the leaflet and asked them to choose all harms that would apply to the HPV vaccination. Out of the six harms listed, three are actually linked to the HPV vaccination: issues at the injection site (fever, redness, pain, and swelling), seasonal allergies, and unspecific arthritis. Seventy-six percent of the girls (95% *CI*: .68%, .83%) and 92% of the parents (95% *CI*: .86%, .95%) in the balanced leaflet group as compared to 48% of the girls (95% *CI*: .38%, .57%) and 54% of the parents (95% *CI*: .45%, .64%) in the unbalanced leaflet group were able to identify the three possible harms after reading the respective leaflet.

5.3. Perceived risk of developing cervical carcinoma

Participants were further asked before and after reading the leaflet to indicate on a 5-point scale, ranging from 1 ("not risky") to 5 ("highly risky"), their perceived risk of developing cervical cancer if they did not have the vaccination. When analyzing the change in perceived risk, we combined the scale points "not risky" (1) and "not very risky" (2) into the category "low perceived risk" and the scale points "very risky" (4) and "highly risky" (5) into the category "high perceived risk". "Somewhat risky" (3) was categorized as "medium perceived risk".

The balanced leaflet reduced the perceived risk of getting cervical cancer without having the HPV vaccine by at least one category (e.g., from medium to low risk) for 51% of the girls and 45% of the parents (girls: r = –.59; parents: r = –.46). Results were mixed for the unbalanced leaflet condition: For 26% of the parents, the perceived risk increased by at least one category (r = –.38), but did not change for the girls (95% *CIs* for effect size included zero).

5.4. Intention to have the HPV vaccine

For the balanced leaflet group, reading the leaflet reduced girls' intention to have the HPV vaccine by 8% points, from 33% to 25% points (r = –.21), and their parents' intention by 8% points, from 39% to 31% points (r = –.20). For the unbalanced leaflet group, girls' intention to have the HPV vaccine increased by 40% points from 24% to 64% points (r = –.60) and their parents' intention by 19% points from 45% to 63% (r = –.38), respectively.

5.5. Actual vaccination decision

About 14 months after the initial part of the study, we investigated participants' actual vaccination decision. We recontacted 132 of the 225 parents who had originally agreed to participate in this second wave (balanced: n = 67, unbalanced: n = 65). At first glance, the actual uptake of HPV vaccination did not differ between the two leaflet conditions (p = .93, r = .01): 22% of the parents in the balanced leaflet group and 23% of the parents in the unbalanced leaflet group reported that their daughter had had the HPV vaccine in the meantime. However, a 2 × 2 analysis on concordance between vaccination intention and actual vaccination decision for each group revealed that for 97% (r_s = .92, p = .00) of the cases in the balanced leaflet group but for only 60% (r_s = 37, p = .08) of the cases in the unbalanced leaflet group did the originally stated vaccination intention also predict the eventual vaccination decision.

6. Discussion

Between 86% and 95% of participants in the unbalanced leaflet condition either overestimated the risk of cervical cancer and the effectiveness of HPV vaccination by at least an order of magnitude or did not know the answer to these questions after they had read the information leaflet on HPV vaccination from the *D. Krebshilfe* (German Cancer Aid). Contrary to the intention of this leaflet, it instead reduced the number of people who correctly understood the risk of cervical cancer and the effectiveness of the vaccination. These findings add to the evidence that unbalanced reporting about medical matters seriously misinforms people (e.g., [24–27].) The balanced leaflet, in contrast, enhanced people's understanding of each of the investigated knowledge dimensions.

Table 4
Changes (in absolute percentage points) in knowledge about the purpose and the benefit of the HPV vaccine from before to after reading the leaflet.

		Change in knowledge about the purpose of HPV vaccination	*Effect size (95% CI)*	Change in knowledge about the benefit of the vaccine		*Effect size (95% CI)*
		Correct answer		Correct estimates	Overestimates	
Girls	Unbalanced leaflet*	+13.9% (n = 102)	r = −.36 (−.52; .18)	−5% (n = 102)	+21.6% (n = 102)	r = −.18 (−.27; −.12)
	Balanced leaflet	+27.5% (n = 121)	r = −.47 (−.60; −.32)	+48.5% (n = 120)	−40.5% (n = 120)	r = −.66 (−.77; −.55)
Parent	Unbalanced leaflet*	0% (n = 103)	r = −.02 (−.21; +.17)	−1.0% (n = 99)	+9.8% (n = 99)	r = −.14 (−.33; +.06)
	Balanced leaflet	+22.2% (n = 118)	r = −.37 (−.51; −.21)	+47.9% (n = 120)	−42.1% (n = 120)	r = −.64 (−.73; −.52)

* Colored boxes highlight decreases in knowledge about the incidence and mortality of cervical carcinoma after reading the leaflet.

Because the unbalanced leaflet reported relative numbers (i.e., large numbers) or numbers without a reference class, many more people judged their risk of developing cervical cancer without having the vaccine to be considerably higher after having read the leaflet than they had previously. Because the balanced leaflet, in contrast, reported all information in transparent absolute numbers (i.e., small numbers) accompanied by a reference class, many participants perceived their risk to be considerably lower and, in fact, in more realistic numbers after reading the leaflet.

People's altered risk perception did translate into the commonly reported impact on people's intention. We saw a decrease in participants' intention to have the HPV vaccine in the balanced leaflet group and an increase in intention in the unbalanced leaflet group. Despite these differences in intention, the two groups did not differ in extent of the real uptake of HPV vaccination. At first glance, these findings suggested that although the balanced information group now knew more about cervical cancer and the efficacy of the HPV vaccine than did the unbalanced information group, these differences did not translate into a difference in actual vaccination behavior. Our study would not have been the first to discover a difference between people's knowledge and their actual health behavior, the so-called knowledge–behavior gap (e.g., [19,20]). However, a closer inspection of our data revealed that the balanced information apparently induced a preventive intention that robustly predicted people's actual vaccination behavior. By contrast, the increase in vaccination intention that was induced by the unbalanced information did not reliably predict the participants' eventual vaccination decision. These findings suggest that phenomena such as the knowledge–behavior gap more likely exist if people are presented with unbalanced rather than balanced health information. We did not find evidence on the use of the heuristic "trust-your-doctor" [23] in our data. For the participants in the balanced leaflet group, we observed no increase from the number of people who stated their intention to have the HPV vaccine to those who actually reported having had the vaccine, whereas for the participants in the unbalanced leaflet group, we observed a pronounced decrease from the number of people who stated their intention to have the HPV vaccine to those who actually reported having had the HPV vaccination.

Our results should be viewed in the light of a potential limitation. The study was conducted at the beginning of 2010, three years after the HPV vaccination was first officially recommended by German health authorities and covered by German health plans for girls aged 12–17 years. Between 2010 and today the quality of information in patient leaflets and media may have substantially improved, and hence it could be argued that the implication of our study may no longer be up-to-date. However, Bodemer et al.'s analysis from 2012 makes it clear that the current standard of information has unfortunately not improved since the year in which we conducted the study.

At the same time, the intentions of our study should not be misconstrued. By no means do we wish to speak out against vaccination or cast doubts on the benefits of prevention. Prevention is an important means of improving public health. However, in keeping with evidence-based medicine and informed decision making, we believe that it is important to inform people transparently about what and what not to expect from a preventive measure under consideration. Withholding information or providing only favorable information ignores the ideal of contemporary medicine: informed (not paternalistic) decisions. Moreover, such intransparent formats are recognized by people: When we asked participants to evaluate the quality of the leaflet, three quarters of the parents and nearly half of the girls in the unbalanced group stated that the leaflet did not help them to understand the benefit and harms of the vaccination. In comparison, only 25% of the parents and 18% of the girls in the balanced group found their leaflet uninformative.

We can only speculate as to the reasons why some public health agencies provide patients with unbalanced health information. One reason might be that the leaflet developers themselves struggle with understanding which statistics are transparent and which are not. Even many licensed medical doctors demonstrate limited understanding of the statistics in their own specialties [27–31,12]. In addition, the use of unbalanced health information might be motivated by the assumption that exaggerating the threat of a disease will more likely encourage people to engage in preventive behavior [32–34]. Our study, however, does not support this view.

Informed decisions require balanced information and balanced numbers that quantify both benefits and harms. Unfortunately, none of the existing German leaflets on HPV vaccination [3,4] follow the guiding principles of evidence-based risk communication. To promote informed decision making and avoid the risk of losing patients' trust, German health agencies should incorporate these principles and strive to provide transparent and balanced medical information.

Conflict of interest

None declared.

Appendix A . Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.vaccine.2013.12.038.

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