Calling the shots

HPV Vaccination and Cervical Cancer: Analysis of Risk Percpetion amongst Young Women and Influences on Parental Decline

This is a public health project by 4th year medical students University of Otago, Wellington 2012

Clients: Regional Public Health - Rukhsana Ali
Cancer Society of New Zealand – Sarah Penno

Supervisors: Des O'Dea
Nick Preval
Lucie Collinson

Our clients had slightly different questions so to present our findings with greater clarity we decided to produce two reports.

Addressing the low Gardasil® uptake in schools: who is declining and why?
For Regional Public Health

Assessing the impact of the Gardasil® vaccination campaign on young women's perceived risk of cervical cancer in New Zealand .
For the Cancer Society of New Zealand

Authors: *Alice Ma, Mary McWatters, Sandeep Naik, Julia O'Flaherty, Nurasiah PG Omar, Nishanthan Ramachandran, Riley Riddell, Brigit Ross, Katie Shillito, Nippun Sofat, Tarucilla Tatui, Jennifer Walker, Tom Wilkinson, Joel Winstanley, and Jess Yager*

Addressing the low Gardasil® uptake in schools: who is declining and why?

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Abstract

Introduction: New Zealand introduced a national Human Papillomavirus (HPV) immunisation programme in 2008 with the aim of reducing cervical cancer associated morbidity and mortality. The Ministry of Health's target of 90% coverage is not currently being achieved. This project aims to explore who is declining the Gardasil® vaccination provided at school for their daughter, and their reasons why.

Methods: We analysed demographic data and parental consent rates collected for all girls in the Wellington region offered the vaccine at school from 2010-2012. We also distributed a survey to parents of year 7-9 girls focusing on why they declined or accepted the vaccine for their daughter.

Results: Consent rates decrease as school decile increases. NZ Europeans have lower consent rates than Maori and Pacific island groups. Both trends remain significant when adjusted for the other, with the highest consent rate in low decile Pacific Islanders (91%) and the lowest consent rate in high decile NZ Europeans (56%).

Non-consenting parents were more likely than consenting parents to have discussed their decision with family and/or friends (odds ratios 5.4 (95% CI 1.5-18.7) and 4.2 (1.5-11.9) respectively). The most common reasons for declining the vaccine related to concern over its safety and the nature of HPV as a sexually transmitted infection. The most common reasons for consenting to the vaccine related to the understanding of severity of cervical cancer, the benefits outweighing the harms and the vaccine being no different from any other.

Conclusions: Higher decline rates are found in high decile and NZ European populations. We identified target areas for further marketing and research to increase consent rates.

Introduction

New Zealand's Human Papillomavirus (HPV) school-based immunisation programme began in September 2008, at a cost of $177 million dollars over five years (1). As of September 2010, New Zealand's national coverage rate was 40% (2), far below the initial 2011 target of 90% (1). Lower coverage means fewer women are protected from cervical cancer, and reduces the cost-effectiveness of vaccination. There is therefore a need to investigate possible reasons for this low uptake.

HPV is transmitted sexually and often causes an asymptomatic infection (3) which will usually resolve within 2 years. However, 20 of more than 100 HPV genotypes have the potential to cause cancer (3,4). Indeed, HPV infection is found in almost all cases of cervical cancer (3). In 2007 it was estimated that 160 women were diagnosed with cervical cancer each year in New Zealand, leading to 60 deaths (1).

The programme uses the vaccine Gardasil® as a complement to the cervical screening program (1). Gardasil® is a quadrivalent vaccine for HPV types 6, 11, 16, and 18 (5). Types 16 and 18 are responsible for 70% of cervical cancer, while types 6 and 11 commonly cause genital warts (1). The vaccine is delivered in 3 doses over 6 months (5). In the long term, the vaccine has the potential to prevent 30 deaths from cervical cancer each year and reduce demands on the cervical screening programme (1). Also the vaccine will help prevent genital warts, anogenital cancer and oropharyngeal cancer (1,4).

Gardasil® is offered to all girls in Year 8 at school and a catch-up program for girls aged 13 to 18 was implemented when it was introduced (1). The vaccine can also be obtained outside of school (1). Younger girls are targeted for vaccination so as to reduce the likelihood of prior HPV exposure and thus maximise the efficacy of the vaccine (6).

Maori have the lowest overall vaccination rates and highest incidence of cervical cancer (1). Priority was therefore given to preventing ethnic inequalities in HPV vaccine coverage (1). Existing New Zealand evidence has shown that HPV vaccine coverage is highest for Maori and Pacific girls, but that HPV awareness is lower among these groups compared to other ethnicities (2).

Existing international literature has found the following factors to be associated with parental consent for HPV vaccination: physician endorsement (7-11), moderate religious beliefs (12,13), social support for the vaccine (9,14,15), child-parent discussions of sexual health (10,16), and parents perception that their daughter is at high risk (12,16). Factors that are associated with parents declining the vaccine are: a lack of relevant knowledge (7,16,17), strong religious beliefs (12,13), higher education (7,18-20), and concerns about vaccine safety (7,9,10,14,19,21,22).

However questions remain. School vaccination staff in the Wellington region have noticed an association between high socioeconomic status (SES) and low parental consent to the vaccine. Robust evidence on the presence of such a trend is lacking, and if it does exist, it may be confounding the previously observed relationships between ethnicity and consent. Additionally, further New Zealand data on factors influencing parents decisions about their daughter receiving the vaccine would help to explain the low consent rate.

Our study therefore aims to investigate the relationship between ethnicity, SES, and parental decline of the HPV vaccine and explore reasons for parental decline with the aim to better inform interventions to improve consent rates for the HPV vaccine in New Zealand.

Methods

Analysis of school parental consent rates by ethnicity and socioeconomic status

This project focused on parental consent to the vaccine at school within the greater Wellington region (including Wellington, Lower Hutt, Upper Hutt, Porirua, and the Kapiti Coast south of Waikanae), where the vaccine is currently offered to school students. The organisation responsible for implementing the HPV vaccine within this region (Regional Public Heath) gave us access to their database for the years 2010-2012. Anonymised data on every girl offered the vaccine for these three years was extracted, including the ethnicity of the girl, the decile of the school she attended, and whether her parents consented to her receiving the vaccine. Decile is a measure of the proportion of students at the school from low SES communities. Decile 1 schools are the 10% of schools with the highest proportion of students from low SES communities and decile 10 schools have the lowest proportion of students from low SES communities (i.e. higher decile indicates higher overall SES status). Decile is used to determine the level of government funding a school is eligible for (23).

If the girls parent/guardian indicated on the consent form that the girl had already received the vaccine or would be getting it from their general practitioner then that girl was excluded from analysis (on the basis of never being in a true position to consent or decline to receiving the vaccine at school).

Currently the vaccine is only offered to girls in year 8 (age 12-13 years), however this has only been the case since 2011. The 2010 data included a number of girls who were older than year 8 (and it was impossible to definitively remove such girls from analysis), and the 2012 data was incomplete (due to it being extracted partway through the year). Therefore,

to provide the most relevant results, the main analysis was conducted on the 2011 data – however, the 2010 and 2012 data were also analysed to see if the same trends emerged.

Consent rates were calculated for each school decile and for each of 4 ethnic groups ("NZ European", "NZ Maori", "Pacific Island", and "Other). The "Pacific Island" group was formed by merging all data for "Samoan", "Tongan", "Niuean", and "Cook Island Maori" (no further specific Pacific Island data were available). Schools were then divided into three groups – low decile (deciles 1-3), mid decile (4-7), and high decile (8-10). Binary logistic regression was used to determine the difference between decile groups after adjusting for ethnicity, and the difference between ethnic groups after adjusting for decile.

Even in the presence of parental consent it is plausible that a girl did not receive the vaccine. We did not calculate actual vaccine uptake rates, which may be lower than consent rates.

Statistical analysis was conducted using SPSS 19.0 (IBM software, New York, USA).

Exploration of factors influencing consent

A local vaccination coordinator provided us with a list of schools that she thought would agree to participate in this study. Guided by this list we contacted sixteen schools, which collectively represented a range of deciles and geographical areas in the greater Wellington region.

Schools that agreed to participate were asked to direct all parents of girls in year 7-9 (age 10-14 years) to an online survey, which was made available for up to 2 weeks. The survey questions were based on prior studies done in New Zealand and Canada on parents' intentions to vaccinate their children (8,19). Questions were asked about demographics and whether or not they consented for their daughter to receive the vaccine.

Participants were then split into two groups: those who consented for their daughter to receive the vaccine at school and those who did not. Participants were excluded if their daughter had never been offered the vaccine, if they weren't involved in the decision to consent/decline, or if they had declined because their daughter had already received the vaccine or would be receiving it outside of school.

Both groups were asked questions about what they thought the vaccine prevented, how happy they were with their decision, and who they talked to about their decision. For each of these questions any differences between groups were tested for significance using a chi-square test, and odds ratios were calculated where possible.

Participants were then provided with a list of factors/reasons that may have influenced their decision and asked to indicate any that applied. The list of reasons was different for each of the two groups to reflect the differing consent statuses. The percentage of participants who agreed with any particular item on the list was calculated and the items ranked accordingly (from most agreed to least agreed).

Ethics approval was obtained from the University of Otago Human Ethics Committee for all parts of this project.

Results

Analysis of school parental consent rates by ethnicity and socioeconomic status

Summary figures for overall consent are given in table 1. These represent all girls in the greater Wellington region offered the vaccine through the school vaccination programme.

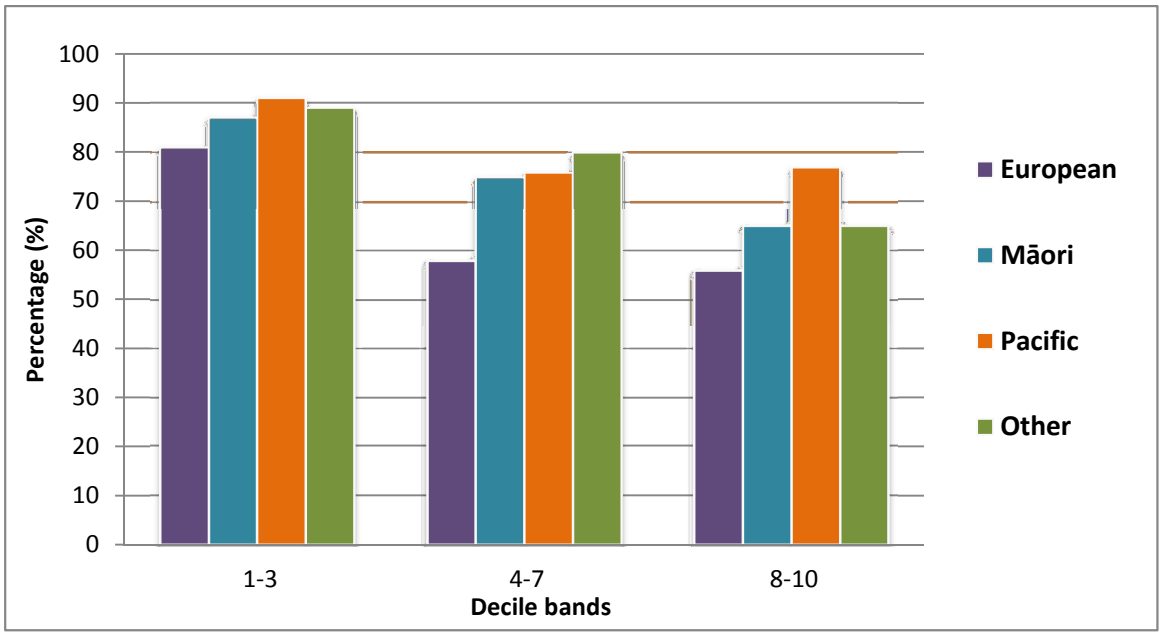
Table 1: Overall consent rate

	2010	2011	2012
Total offered vaccine	12 242	2 529	2 659
Consent form not returned	2 766	70	44
Excluded*	108	21	298
Consent status unknown **	309	54	1 545
Full parental consent given	5 104	1 558	280
Parental decline recorded	3 955	826	492
Consent rate ***	56.3%	65.3%	36.3%

** Exclusion criteria: girl had already received vaccine or would be vaccinated by doctor instead.*
*** (total offered vaccine) – (excluded + consent form not returned + full parental consent given + parental decline recorded).*
**** (full parental consent given)/(full parental consent given + parental decline recorded).*

Figure 1 shows the consent rates for 2011 stratified by ethnicity and decile. Consent rates declined with increasing decile across ethnic group, while NZ Maori and Pacific Islanders had higher consent rates than NZ Europeans in all 3 decile bands. The highest consent rate (91%) was in low decile Pacific Islanders while the lowest (56%) was in high decile NZ Europeans.

Figure 1: 2011 consent rate by ethnicity and decile



The results of binary logistic regression analysis are given in tables 2 and 3. For 2011 all 3 decile bands were significantly different from each other after adjusting for ethnicity. The NZ European consent rate was found to be significantly lower than the NZ Maori and Pacific Island consent rates after adjusting for decile, however the difference between the NZ Maori and Pacific Island consent rates was not statistically significant ($p = 0.10$). The overall effect of decile and overall effect of ethnicity were both statistically significant, at $p < 0.001$.

Tables 2 and 3 also display results for 2010 and 2012. For 2010 the same trends are seen and all comparisons (including NZ Maori compared to Pacific Island) are statistically significant at $p < 0.001$. Despite its weaknesses, the 2012 data also shows the same trends emerging. No ethnic comparisons involving Pacific Islanders were made in 2012 as there was no data available on Pacific Islanders in the mid decile group.

We did not perform any ethnicity comparisons involving the “other” group as this group is poorly defined and likely to include a large number of heterogeneous ethnicities. We felt that any such results would not be useful.

Table 2: School parental consent rates by Decile (adjusted for ethnicity)

	2010		2011		2012	
	Odds ratio (95% CI)	p-value*	Odds ratio (95% CI)	p-value*	Odds ratio (95% CI)	p-value*
Low compared to mid	1.82 (1.55-2.14)	<0.001	2.42 (1.61-3.65)	<0.001	4.69 (2.64-8.30)	<0.001
Mid compared to high	1.22 (1.10-1.36)	<0.001	1.30 (1.05-1.60)	0.01	0.99 (0.67-1.46)	0.97
Low compared to high	2.32 (1.99-2.71)	<0.001	3.38 (2.34-4.87)	<0.001	5.96 (3.59-9.92)	<0.001

* *p-values were derived from the chi-square distribution*

Table 3: School parental consent rates by ethnicity (adjusted for decile)

	2010		2011		2012	
	Odds ratio (95% CI)	p-value*	Odds ratio (95% CI)	p-value*	Odds ratio (95% CI)	p-value*
Māori compared to European	2.16 (1.88-2.49)	<0.001	1.67 (1.28-2.18)	<0.001	2.70 (1.73-4.22)	<0.001
Pacific Island compared to European	3.04 (2.51-3.69)	<0.001	2.38 (1.56-3.61)	<0.001	Not calculated	
Pacific Island compared to Māori	1.47 (1.19-1.83)	<0.001	1.45 (0.93-2.27)	0.10	Not calculated	

* *p-values were derived from the chi-square distribution*

Exploration of factors influencing consent

Ten schools agreed to participate. Two were decile 2, four were decile 10, and the remaining were deciles 5, 7, 8, and 9. They were spread out over the Wellington region. However, only 7 of these schools actually provided any survey responses.

In total we received 117 responses with 31 exclusions; 1 did not consent to participate, 4 left the survey blank, 20 indicated that the daughter had not been offered the vaccine (all had a year 7 daughter) and 6 indicated the daughter would receive it outside the school programme. This left us with 86 participants. Of these 51 (59.3%) consented to vaccination

and 35 (40.7%) did not. We are unable to calculate a response rate as we do not know how many parents were sent the survey link by the schools.

Cohort descriptors are provided in table 4. Although the response obtained from parents in low and mid decile schools was disappointing, a strong response was obtained from the high decile schools, allowing us to explore underlying reasons for the low consent rate in this group.

Table 4: Demographics of the survey participants

	Participants	Number	Percentage
Gender	Female	78	90.7
	Male	7	8.1
	Unknown	1	1.2
Qualifications	None	1	1.2
	High School	18	20.9
	Undergraduate degree	43	50
	Postgraduate	24	27.9
Ethnicity	NZ European	71	82.6
	NZ Maori	6	7.0
	Pacific Island*	0	0
	Chinese	3	3.5
	Indian	1	1.2
	Other	13	15.1
Year Level of Daughter**	7	5	5.8
	8	46	53.5
	9	35	40.7
Decile of school	Low 1-3	0	0
	Mid 4-7	2	2.3
	High 8-10	84	97.7

** Pacific Island includes Samoan, Cook Island Maori, Tongan, and Niuean*
*** If more than one daughter fell into the Year 7-9 category, the questions were answered as they related to the eldest daughter.*

Parents were asked who they discussed their decision with, by ticking all that applied on a supplied list. Responses are shown in table 5. Non-consenters were more likely to have discussed their decision with all 5 people/groups on the list. This difference was significant in the categories of discussing with extended family and friends, with odds ratios for not consenting of 5.4 ($p = 0.005$) and 4.2 ($p = 0.005$) respectively.

Table 5: Who the deciding parent discussed consent with

	Consent		Non-consent		OR (95% CI)	p-value*
	n	%	n	%		
Partner	35	69	28	80	1.8 (0.7-5.1)	0.24
Daughter	32	63	28	80	2.4 (0.9-6.5)	0.09
Extended Family	4	8	11	31	5.4 (1.5-18.7)	0.005
Friends	7	14	14	40	4.2 (1.5-11.9)	0.005
Healthcare Professional	13	26	10	29	1.2 (0.4-3.1)	0.75
No one	6	12	1	3	0.2 (0.02-1.9)	0.14

** p-values were derived from the chi-square distribution*

We found no statistically significant differences between the consent and non-consent groups when looking at exposure to sources of information regarding the vaccine (Table 6). Pamphlets/brochures and the media were the most commonly reported sources of information, while talking to a health care professional was the least reported.

Table 6: Sources of information recalled by patients

	Consent		Not consent		OR (95% CI)	p-value*
	n	%	n	%		
Talked with a HCP about the vaccine	22	43	13	37	0.8 (0.3-1.9)	0.58
Read pamphlets/brochures	47	92	35	100	n/a	0.09
Personal research	23	45	22	69	2.1 (0.9-5.0)	0.11
Media	48	94	34	97	2.1 (0.2-21.3)	0.51

** p-values were derived from the chi-square distribution*

Perceived benefits of the vaccine for both groups are shown in Table 7. There was a statistically significant difference between the two groups with regard to the belief that the vaccine prevents cervical cancer. Additionally, the consenting group was more likely to (correctly) think the vaccine prevents genital warts and (incorrectly) think the vaccine prevents ovarian cancer, however neither of these differences were statistically significant.

Table 7: Agreement with the statement "I think that this vaccine prevents…"

	Consent		Not consent		OR (95% CI)	p-value*
	n	%	n	%		
Common cold	0	0	0	0	n/a**	n/a
Cervical cancer	51	100	31	89	n/a**	0.01
Anal cancer	3	6	2	6	1.0 (0.2-6.1)	0.97
Ovarian cancer	8	16	2	6	0.3 (0.1-1.6)	0.16
Genital warts	16	31	8	23	0.6 (0.2-1.7)	0.39

** p-values were derived from the chi-square distribution*
*** odds ratios were unable to be calculated when the proportion in either group was 0% or 100%*

Parents were asked to rate their happiness with their decision to consent or not consent their daughters for vaccination on a 5-point Likert-type scale ranging from "very unhappy" to "very happy". 96.1% of the consent group and 91.4% of the non-consent group were either "somewhat happy" or "very happy". A chi-square test showed no significant difference between the groups (p = 0.38).

Agreement with supplied reasons for consent/non-consent is shown in tables 8 and 9. The reasons were presented as lists, with respondents asked to tick those which influenced their decision. Participants could select multiple options.

Table 8: Reasons for consent (ranked most common to least common)

	Number	Percentage
Cervical cancer is a serious disease	42	82.4
The benefits of the vaccine outweigh the harm	40	78.4
I have consented to all vaccines offered to my daughter (and this vaccine is no different)	36	70.6
It is important for my daughter to get this vaccine before she is involved in any sexual activity	29	56.9
I am concerned about my daughters health	25	49.0
I trust the health care system	23	45.1
The vaccine is safe	17	33.3
I know someone who has had cervical cancer	9	17.6
A doctor advised me that this vaccine would be a good idea for my daughter	6	11.8
A nurse advised me that this vaccine would be a good idea for my daughter	1	2.0
Other	3	5.9

Table 9: Reasons for non-consent (ranked most common to least common)

	Number	Percentage
This vaccine is too new and more research is needed	26	74.3
I am concerned about the safety of this vaccine	21	60.0
My daughter is too young	15	42.9
My daughter is not sexually active	14	40.0
I will educate my daughter on abstinence and/or safe sex instead	9	25.7
My daughter is not at great risk of cervical cancer	8	22.9
I don't think I received enough information to make an informed choice	7	20.0
I felt rushed/pressured to make a decision	6	17.1
I don't trust pharmaceutical companies	5	14.3
Information I read on the internet about it	5	14.3
Medical reasons (e.g. prior allergic reaction to a vaccine)	2	5.7
I don't want to expose my daughter to too many needles	2	5.7
I don't trust the public healthcare system	2	5.7
It might encourage dangerous and/or inappropriate sexual behaviour	2	5.7
A doctor advised me that my daughter shouldn't get it	1	2.9
I have a cultural and/or religious objection	0	0.0
Other	7	20.0

Consenting parents were asked if they felt they received the right amount of information before they made their decision; 98.0% thought they received the right amount of information, and 2.0% felt they didn't have enough information. Nobody indicated they received too much information.

Discussion

Analysis of school parental consent rates by ethnicity and socioeconomic status

This study has found a strong relationship between consent to the HPV vaccine and both SES and ethnicity. 2011 data clearly demonstrates parental decline increasing with higher school decile, and a lower consent rate in NZ European parents compared to Maori and Pacific Island parents. Binary logistic regression demonstrated that these two effects both remain significant after adjusting for the other. Although the 2010 and 2012 data are of less value to answer this study question they demonstrate these same results, supporting the identified trends. Given that we excluded girls who received the vaccine privately these

trends are unlikely to be due to higher decile parents choosing for their daughters to receive the vaccine outside of school.

The major strength of this component of our study was the ability to include all eligible girls within a large geographic region.

However, there were three important weaknesses.

Firstly, as outlined previously, some girls had to be excluded from analysis. There was therefore potential selection bias, although we do note that only 5.7% of the cohort was excluded.

Secondly, the study was unable to adjust for confounders beyond those of ethnicity and SES and therefore there may be factors unaccounted for that may be influencing the results.

Finally, there were weaknesses with our grouping of study participants. Firstly, school decile is only a surrogate for SES: some parents at low decile schools will be relatively affluent, and some parents at high decile deciles will have a relatively low SES. Secondly, our "Pacific Island" group only included 4 Pacific Island ethnicities. This was unavoidable given the nature of the database we accessed, but it does mean that many Pacific Island ethnicities will have been classified as "other". Furthermore, the heterogeneity of the "Pacific Island" and "other" groups makes interpretation difficult, particularly in the case of the latter, where we didn't perform any analyses for this reason. We do not feel that this compromises our conclusions, but it does represent a lost opportunity.

Exploration of factors influencing consent

When presented with a list of 16 possible reasons for declining, non-consenting parents were most likely to identify with reasons relating to safety of the vaccine ("the vaccine is too new and more research is needed", "I am concerned about the safety of this vaccine"). Another common theme was their opinions surrounding their daughters' sexual activity ("my daughter is too young", "my daughter is not sexually active"). The non-consenting group was significantly more likely than the consenting group to have discussed their decision with extended family and friends.

This is consistent with prior research which shows that higher education (8,19,22) and concern for vaccine safety (8,10, 11,15,16,20,23) are associated with a higher decline rate.

Although no other significant differences between consenters and non-consenters were found, we were limited by a small sample size (evidenced by the wide confidence intervals).

We therefore do not feel that we can conclude that the groups were similar in their responses to any survey question. In particular, the odds ratios for non-consent associated with talking to their daughter about this decision, and having done personal research into the vaccine were both greater than 2, with p-values of 0.09 and 0.10 respectively. These could easily have proven to be significant factors if our cohort was larger.

The most common reasons for parents to consent are presented in Table 8. Despite prior literature suggesting physician endorsement as a major contributor to consent (8-12), only 12% of our consenting cohort indicated that the decision to vaccinate was influenced by the advice of a doctor and only 22% recalled talking to a healthcare professional about the vaccine. However, the data is consistent with reported trends for consent to be more likely where the parents perceive their daughter to be at high risk of cervical cancer (13,17). The 5 most popular reasons in our cohort carry the connotation of cervical cancer being serious and of the girl being at risk.

57% of consenting parents thought that it was important for their daughter to get the vaccine before engaging in any sexual activity. This is an interesting contrast to the previously mentioned attitudes of the non-consenting group.

A particular strength of this study is that the respondents represent high decile groups, allowing for exploration of this group of particular interest. In addition, there were a proportional number of consenters and non-consenters who responded, meaning we could directly compare the two.

This study was limited by a low response rate. Although we are unable to calculate an exact response rate, we received only 117 responses from 7 schools, and our cohort is non-representative, with a strong predominance of female respondents with daughters at high decile schools. We think that the low response from low decile schools could be partially due to a lower access to internet as we used an online survey. We were not able to explore the reasons for non-consent in the low decile group or other ethnicities. The low number of responses we received reduced our study power and is likely to have introduced selection bias. In particular, our respondents are likely to hold particularly strong opinions about the vaccine.

Implications

Our data show that current parental consent in the Wellington region is falling short of that required to meet national uptake targets. We have identified particularly low consent rates among affluent parents and NZ Europeans, and suggest that overall vaccine uptake could potentially benefit from an expansion of marketing to further target these groups.

Exploration of reasons for decline among a high decile parental cohort has demonstrated three important factors: concern about the safety and recency of the vaccine, a belief that vaccinating against a sexually-transmitted virus is unnecessary at the age of 12, and social discussion. Future marketing could benefit from a focus on reassuring parents of the safety of the vaccine, communicating the reasons why it is offered at year 8, and the use of people who the low-consenting population can relate to.

We are reluctant to comment on reasons for the higher rate of consent in the low decile and Maori/Pacific groups and feel this phenomenon warrants more research. In particular we would advise caution about labeling it as positive. For example, if it were found to be linked to lower knowledge about the vaccine and therefore impaired informed consent, this would not necessarily reflect a successful vaccination campaign.

It has been previously suggested that, where vaccine uptake is low, herd immunity can be more effectively achieved by including boys in the vaccination programme (24,25). The inclusion of boys has received significant consideration in the USA (26) and Canada (27) and has been recently announced in Australia (28). If uptake rates fail to improve in future this could be an option for New Zealand to consider.

Other areas that would benefit from future research include demographics of girls receiving the vaccine outside of school (e.g. from their GP), further exploration of what media sources have the most influence on the decision to vaccinate, and analysis of actual vaccine uptake by ethnicity and school decile.

Conclusion

Higher parental decline for the administration of HPV vaccine is evident in high decile and New Zealand European groups. Important factors leading to such decline include concern about vaccine safety and its recency, concern about its necessity in year 8 (given that HPV is sexually transmitted), and the influence of social circles. Consideration of these factors could inform marketing campaigns to potentially increase national parental consent rates.

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Appendix: Selected Quotes from Survey

As a part of the survey administered to parents of year 7-9 girls we provided a free-text box where respondents could write comments about their decision to consent/not consent to their daughter receiving the Gardasil® vaccine.

We did not formally analyse these comments in any way, and therefore made no mention of them in the body of this report. However, we think they are of interest and present a selection of them below.

"I heard (the vaccine) only remained effective for 5 years so would be 'worn off' by the time my daughter was 17."

"My daughter is really unlikely to engage in sexual activity before age 16 as she is well supervised."

"Abstinence is a safer and more effective way of preventing cervical cancer."

"…is quite a new vaccine, and there seems to still be uncertainties… The door is in no way closed to her having the vaccine in the future."

"I don't want to expose my daughter's beautiful body to a vaccine that we don't know the effects of years down the track."

"Smear tests are a far more effective tool for reducing cervical cancer than this vaccine will ever be."

"I heard some stories (from friends) which, while unproven, were enough to put me off allowing my daughter to have the vaccine."

"I… have never heard of anyone getting this cancer. My thoughts are why not immunise for throat cancer, or bowel cancer, or lung cancer, etc…"

"I think the benefits at this point outweigh the risk."

"Any vaccine that can prevent cancer at any stage of life is a gift."

"It is a shame that this technology was not available 20 years ago so that two of my best friends did not have to die, despite having regular pap smears and other medical intervention."

Assessing the impact of the Gardasil® vaccination campaign on young women's perceived risk of cancer in New Zealand.

Alice Ma, Mary McWatters, Sandeep Naik, Julia O'Flaherty, Nurasiah PG Omar, Nishanthan Ramachandran, Riley Riddell, Brigit Ross, Katie Shillito, Nippun Sofat, Tarucilla Tatui, Jennifer Walker, Tom Wilkinson, Joel Winstanley, and Jess Yager

Abstract

Background**:** Human papillomavirus (HPV) infection is present in almost all cases of cervical cancer and each year 160 women are diagnosed with cervical cancer in New Zealand, leading to 60 deaths, with significant ethnic and socioeconomic inequities in outcomes. In 2008, New Zealand implemented a predominantly school based national HPV vaccination (Gardasil®) programme targeting year 8 school girls.

Aim**:** To assess current levels of knowledge in young women in New Zealand about HPV, cervical cancer, Gardasil® and the cervical screening programme; and whether this has been influenced by introduction of the national vaccination campaign.

Method: Data was collected via an online questionnaire. We compared two groups: school girls in year nine (12-14 years old) and year 12 (16-17 years old) that were exposed to the vaccination campaign with young women aged 23 to 28 years old that were unexposed or had limited exposure to the vaccination campaign.

Results: Sixty one percent of school girls had received the vaccine, while only 11% of young women had received the vaccine. Eighty three percent of young women who did not receive the vaccine reported never being offered it. Young women and school girls both overestimated the incidence of cervical cancer ($p < 0.001$). There was no major difference between the study groups in regards to the knowledge of benefits from Gardasil® and the need for future cervical cancer screening.

Conclusion: The risk of cervical cancer was overestimated and the most common age for any cancer was falsely identified by both school girls and young women in Wellington. It is quite possible that this distortion in risk perception was influenced by the national vaccination campaign for HPV; however, more research is required into this matter.

Introduction

Even when delivered with the best intentions, public health campaigns run the risk of distorting public knowledge. When these campaigns involve an emotionally charged topic such as cancer, the risk of distortion merits investigation. New Zealand implemented a publicly funded national human papillomavirus (HPV) vaccination programme in 2008 (1), which raises the issue of distortion of cancer risk perception.

Although over 90% of HPV infections usually resolves without treatment in two years and are often asymptomatic (2), they still have the potential to cause cancer. Up to twenty of the over 100 identified HPV genotypes harbour this potential (1). HPV infection is thought to be present in almost all cases of cervical cancer (3, 4), and is also associated with penile, vulval, vaginal, anogenital and oropharyngeal cancer, along with genital warts (5). Every year 160 women are diagnosed with cervical cancer in New Zealand leading to 60 deaths, with significant ethnic and socioeconomic inequalities in outcomes (1). New Zealand has had a cervical cancer screening programme since 1990 (1).

Gardasil® is a quadrivalent vaccine for HPV types 6, 11, 16, and 18 (6). Types 16 and 18 are responsible for 70% of cervical cancer, while types 6 and 11 commonly cause genital warts (1). Gardasil® is a three dose vaccine given over a 6 month period (month zero, two and six) costing approximately $NZ 500 for all males, and for females not falling within the fully funded age range of 12 to 20 (7, 8). New Zealand started a predominantly school based national immunisation program with Gardasil® in 2008 with a long-term focus on vaccinating girls in year 8 (aged 12-13). A temporary catch up programme was included in schools for girls aged 13 to 18 (9). National target coverage rates have been set for 90% of all eligible year 8 school girls to be vaccinated by 31st December of that year from 2011 onwards (1). At the time the programme was allocated $NZ 177 million for a five year period (1). It has the long-term potential to prevent 30 deaths from cervical cancer each year, prevent HPV related morbidity, and reduce demands on the cervical screening programme (1).

Given the scale of the programme and the associated marketing campaign, there may have been significant distortion of perception amongst young women towards cervical cancer risk. However published research in this area is limited.

Studies performed in United States of America (USA) and Australia on comparable populations have investigated knowledge of HPV after the approval of Gardasil vaccine in USA and the implementation of the national vaccination programme in Australia. The American studies involving women with a mean age of 19-21 showed that over 80% were aware of an association between HPV and cervical cancer following the vaccination programme (10-12). Results in two Australian studies were variable, with awareness of the above association in 73% of 18-25 year old females who had heard of HPV (13), and 35% of women aged 14-20 years old (14). However, evidence suggests a lower awareness of

specific HPV knowledge. Two Australian studies found that only 38-45% of participants knew the primary mode of transmission to be sexual (14, 15). A number of studies have identified media as the primary source of such information on HPV (11, 14, 15).

Other studies have investigated individuals' perceived susceptibility to HPV infection and cervical cancer. Studies involving both male and female participants with a mean age of 19 and 20 have found perceived risk of HPV infection to be 44% and 53% respectively (11, 16). An Australian study involving female participants with a mean age of 22 found 97% of its participants believed they were at risk of HPV infection and 95% at risk of developing cervical cancer (17). Another Australian study did not find a statistically significant difference in the perceived vulnerability to cervical cancer between HPV vaccinated and non-vaccinated participants (18). This same study found that less than 5% of participants knew the correct cervical cancer screening guidelines (18), while a further study found no significant difference in overall knowledge of screening between vaccinated and non-vaccinated participants (17).

However, as far as we know previous research has not compared participants' perceived risk with their true risk of cervical cancer, nor has there been an investigation into how perceptions are influenced by specific cancer prevention programmes. This project aims to assess current levels of knowledge in young women in New Zealand about HPV, cervical cancer and the associated vaccine and screening programmes. Of particular interest is people's awareness of cervical cancer risk and how this may have been affected by the introduction of the national vaccination programme.

Methods

Our study population was secondary school girls in year 9 (12-14 years old) and year 12 (16-17 years old), and young women aged 23 to 28. Year 9 and 12 girls were selected to gain a comprehensive representation of the cohort eligible for the free HPV vaccine (Gardasil®), the exposed group in regards to the associated media campaign. Year 9 girls were chosen because they were the cohort which had most recently received the vaccination. Year 12 girls were chosen because this group did not require parental consent to participate in the survey and are likely to have a higher school enrolment rate as opposed to year 13 girls. We selected only two year groups in order to minimise the administration burden for schools and due to time constraints of the study. Women aged 23 to 28 were chosen as a reasonable comparison group as they were the youngest age range not eligible for the free HPV vaccine and likely to have had less exposure to the associated media campaign. For these reasons they were considered the unexposed group.

Two surveys were constructed and piloted to a small group of study investigators, after which minor adjustments were made before survey dissemination. The survey questions were designed to investigate the demographics of participants and their knowledge of and exposure to the Gardasil® vaccine. One survey was aimed at the school girls, the other at the young women. The two surveys were similar with adjustments made to ensure they were appropriately targeted to each cohort. All participants were asked a set of identical questions about the incidence of breast, cervical, lung and bowel cancer among females in New Zealand. They were asked to estimate the incidence of cancer by choosing one of seven possible incidence ranges per year (e.g. 50-149, 150-499, etc.). The knowledge of participants was further assessed by asking "what age are women/girls most likely to be diagnosed with any form of cancer", and with two other questions assessing their awareness of the need for regular cervical cancer screening. The study was approved by the University of Otago Human Ethics Committee and participant anonymity was preserved.

Year 9 and year 12 students were recruited from a list of schools in the greater Wellington region as defined by the Wellington Regional Council (19). This list was based on recommendation by a local vaccination coordinator, who thought these schools were likely to be approachable. The schools were split into three categories, low decile (1-3), medium decile (4-7) and high decile (8-10). Decile is an assigned number from 1 to 10 that indicates the extent to which it draws students from low socio-economic communities, where decile 1 represents the 10% of schools with the highest proportion of these students (20). Three schools from each category were randomly selected and contacted to gauge interest in participation with the aim of recruiting one school from each category. When a school showed interest they were followed up with an information letter and further arrangements regarding school visits were organised. The appropriate number of classes to include in the study was negotiated with the school, with our minimum requirement being two year 9 classes (due to suspected low parental consent rates) and one year 12 class. Consent forms

to year 9 students and information sheets to year 12 students were distributed via teachers during school time. Consent forms were to be signed by parents and returned to the school within a time period of at least 3 days. After this period the surveys were administered to the willing year 12 students and the year 9 students who had received parental consent.

The young women cohort was recruited through a selection of two workplaces, a gym, a local Muslim community and through a local University Student Health Services.

One thousand female students in our target age-range were randomly selected from a list supplied by a local University Student Health services and sent an email with a link to an online version of the survey. One workplace also chose this distribution method and emailed the survey link to women who met the study age criteria. The other work place, gym and local muslim community were surveyed via paper copy. These were made visibly available to female employees and members in a position deemed suitable by managerial staff in workplaces and gym. Secured boxes were provided for collection of completed surveys. Muslim community were recruited by an investigator contacting acquaintances.

Answers to the questions regarding the incidence of breast, cervical, lung and bowel cancer among females in New Zealand were compared to the true incidence and a sign test was used to compare the proportion of respondents who over-estimated the incidence to the proportion who under-estimated the incidence. This allowed us to test for statistically significant under-estimation or over-estimation across the overall group. The overall distribution for each cancer was compared between the two participant groups (school-aged girls and young women) using the Mann-Whitney U test. In addition, for each participant group, a chi-square test was conducted for differences between the distribution of risk perception of the four cancers and a Friedman test (a non-parametric equivalent of the repeated-measures ANOVA) was conducted to explore how participants ranked the incidence of each cancer compared to the other three. Statistical analysis was conducted using SPSS 19.0 (IBM software, New York, USA).

Results

The final cohort size was 64 for the 13-18 year old group, and 144 for the 23 to 28 year old group. The average age in the 13-18 year old group was 16 and in the 23 to 28 year old group was 25 (Table 1).

Table 1: The sample populations; school girls and young women.

	School Girls (13-18 years old)	Young Women (23-28 years old)
Total Responses	74	165
Did not Consent	3	4
Excluded*	7	17
Cohort Size	64	144
Mean Age	15.6	24.7

**Exclusion Criteria: male, live outside Wellington, wrong age*

The predominant ethnicity in both groups was 'NZ European', followed by 'Other' (Table 2).

Table 2: Ethnic make-up of the school girls and the young women.

	School Girls (13-18 years old)	Young Women (23-28 years old)
NZ European	63%	68%
Māori	3%	6%
Samoan	8%	1%
Chinese	11%	6%
Indian	2%	1%
Other	19%	29%

Note: Participants could choose multiple ethnicities

Tables 3 and 4 show the exposure to Gardasil® and the associated information in both study groups. The school girls were more likely to have received the vaccine, to have talked to peers about it, to be satisfied with the amount of information they had received about it, and to perceive a high vaccine uptake among their peers. The most common reason for not receiving the vaccine in the older group was "I've never been offered the vaccine."

Table 3: Exposure of the Gardasil vaccination programme for the school girls and the young women.

INFORMATION ON THE VACCINATION PROGRAMME				
Question	**School Girls (13-18 years old)**		**Young Women (23-28 years old)**	
Have you been given the HPV/cervical cancer vaccine (Gardasil)?	Yes No Don't know I haven't heard of it	61% 31% 5% 1.5%	Yes No Don't know I haven't heard of it	11% 83.5% 1.5% 4%
Do you feel you had the right amount of information about this vaccine when deciding to get/not get it?	Didn't have enough Right amount Too much	36% 64% 0%	Didn't have enough Right amount Too much	69% 30% 1%
SOCIAL ASPECTS OF THE VACCINATION PROGRAMME				
Do you remember talking to your peers/friends about this vaccine?	Yes No Not sure	70% 11% 19%	Yes No Not sure	51% 43% 6%
How many of your classmates/peers/friends have had this vaccine?	All Most Few None Don't know	3% 57% 26% 0% 14%	All Most Few None Don't know	0% 3% 22% 29% 46%
Have you personally done any research into this vaccine?	Yes No	6% 94%	Yes No	23% 77%
MEDIA ASPECTS OF THE VACCINATION PROGRAMME				
	School Group (13-18 years old)		**Young Women (23-28 years old)**	
Do you remember being talked to about this vaccine at school (school group) **OR** *Do you remember talking with a healthcare professional about this vaccine (young women)?*	Yes No	84% 16%	Yes No	20% 80%
Do you remember reading anything about this vaccine? (School group) **OR** *Do you remember reading any pamphlets/brochures about this vaccine? (young women)*	Yes No	65% 35%	Yes No	40% 60%
Do you remember hearing about this vaccine outside of school? (school group) **OR** *Do you remember hearing about this vaccine in the media? (young women)*	Yes No	56% 44%	Yes No	88% 12%

Table 4: Young women's (aged 23-28 year old) reasons for not being vaccinated for HPV

Responses	Percentage who selected the response
I've never been offered the vaccine	82.5%
It's too expensive	17.5%
None of the above (other factors)	13.3%
I am concerned about side-effects	10.8%
I don't need it	5.8%
I don't think its works	2.5%
My parents/other family/friends/ don't think I need it	1.7%
I have religious and/or cultural objection	0.8%

Note: Participants could choose multiple options.

There was no major difference between school girls and young women in regards to knowledge of the benefits of the HPV vaccination and the need to have screening for cervical cancer (Table 5).

Table 5: Knowledge of the Gardasil vaccination programme and cervical cancer for the school girls and the young women

Question	School Girls (13-18 years old)		Young Women (23-28 years old)	
INFORMATION ON HPV VACCINATION				
This vaccine helps to prevent cervical cancer…	Yes No	100% 0%	Yes No	98% 2%
This vaccine helps to prevent genital warts…	Yes No	10% 90%	Yes No	27% 73%
INFORMATION ON FUTURE SCREENING				
Do women who have had this vaccine need regular check-ups for cervical cancer (i.e. Smear tests)?	Yes No Don't Know	61% 2% 37%	Yes No Don't Know	83% 1% 16%
Do women who HAVE NOT had this vaccine need regular check-ups for cervical cancer (i.e. Smear tests)?	Yes No Don't Know	80% 2% 18%	Yes No Don't Know	94% 1% 5%

Figure 1 shows responses to the question "at what age are women/girls in New Zealand most likely to get any form of cancer". The responses were similar between groups, with both groups favouring the option "40-54 years". (The correct answer is "70 and over")

Figure 1: Perception of age of cancer diagnosis (the arrow indicates the correct answer)

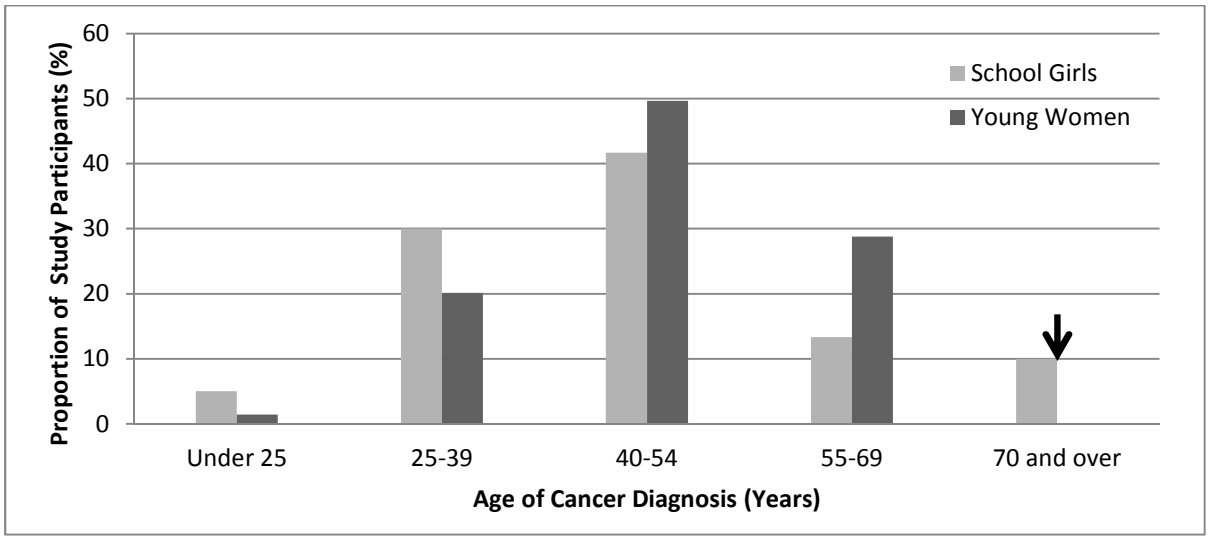


Figure 2 shows the perceived incidence of the 4 cancers that were asked about.

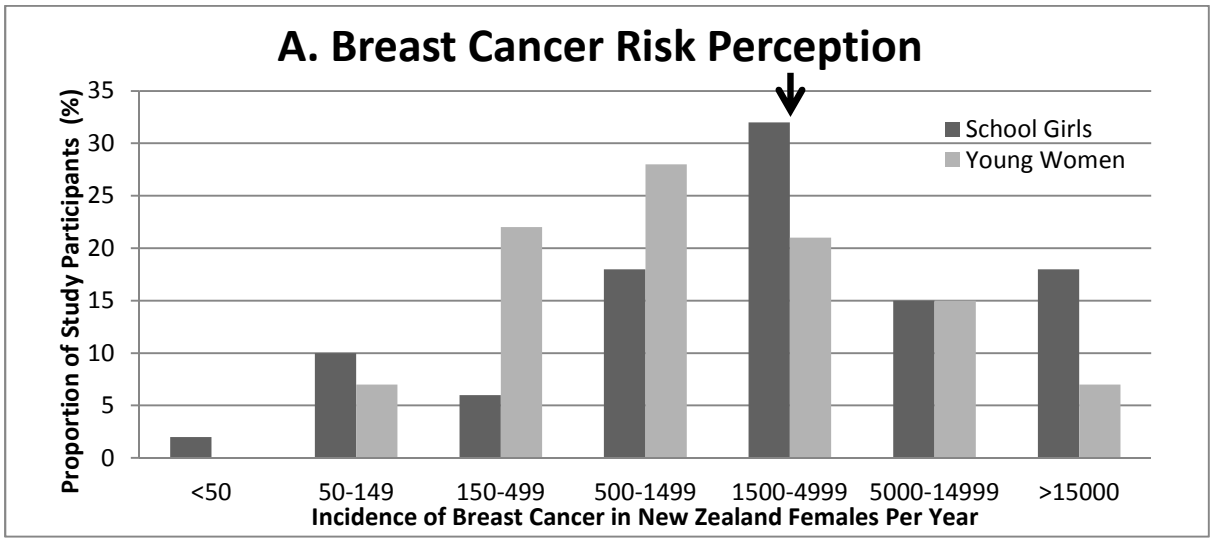
The school girls overestimated the incidence of cervical cancer ($p < 0.001$) and underestimated the incidence of lung cancer ($p = 0.05$) to a statistically significant level. They neither underestimated nor overestimated the incidences of bowel and breast cancer ($p = 0.99$ and $p = 0.88$ respectively).

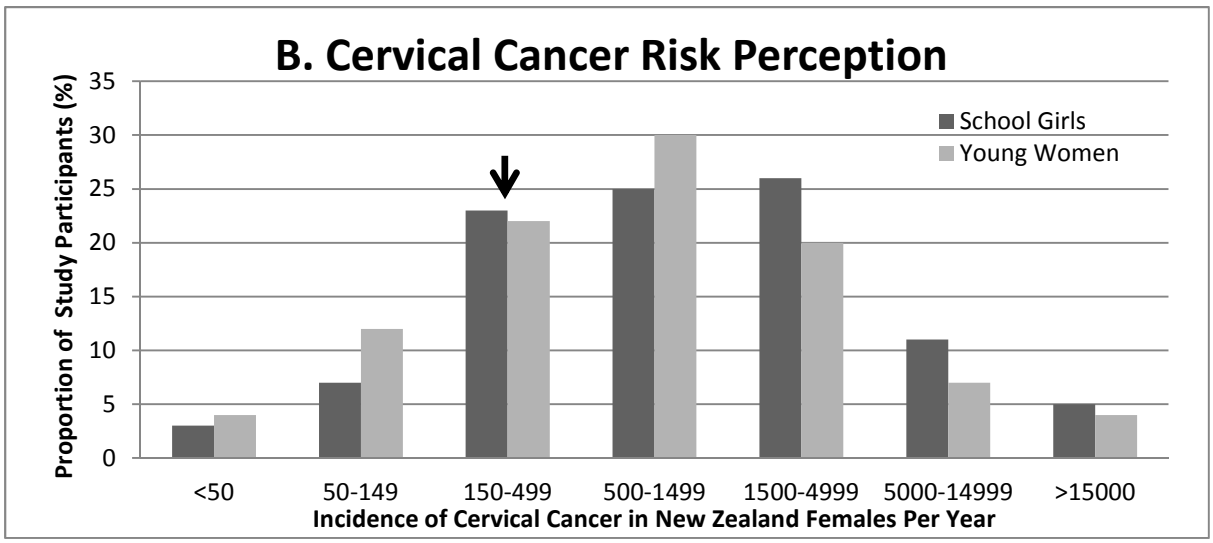
The young women overestimated the incidence of cervical cancer ($p < 0.001$) and underestimated the incidences of breast and bowel cancer ($p < 0.001$ for both) to a statistically significant level. They neither underestimated nor overestimated the incidence of lung cancer ($p = 0.065$).

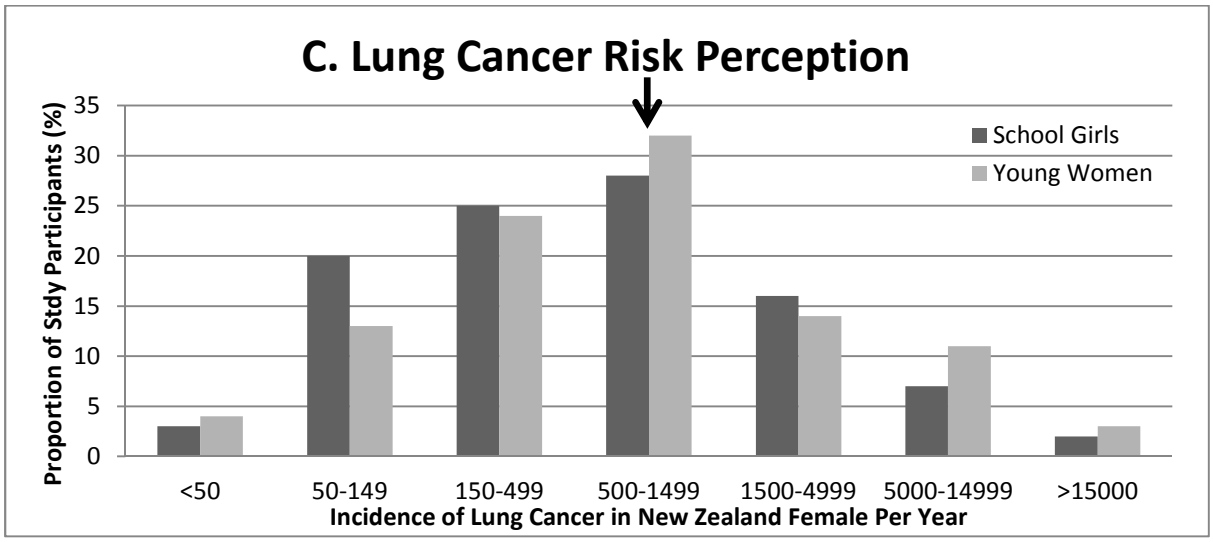
Statistically significant differences between the two groups were found for breast cancer (school girls perceived a higher incidence, $p = 0.02$) and bowel cancer (school girls perceived a higher incidence, $p = 0.006$), but not for cervical ($p = 0.15$) or lung cancer ($p = 0.34$).

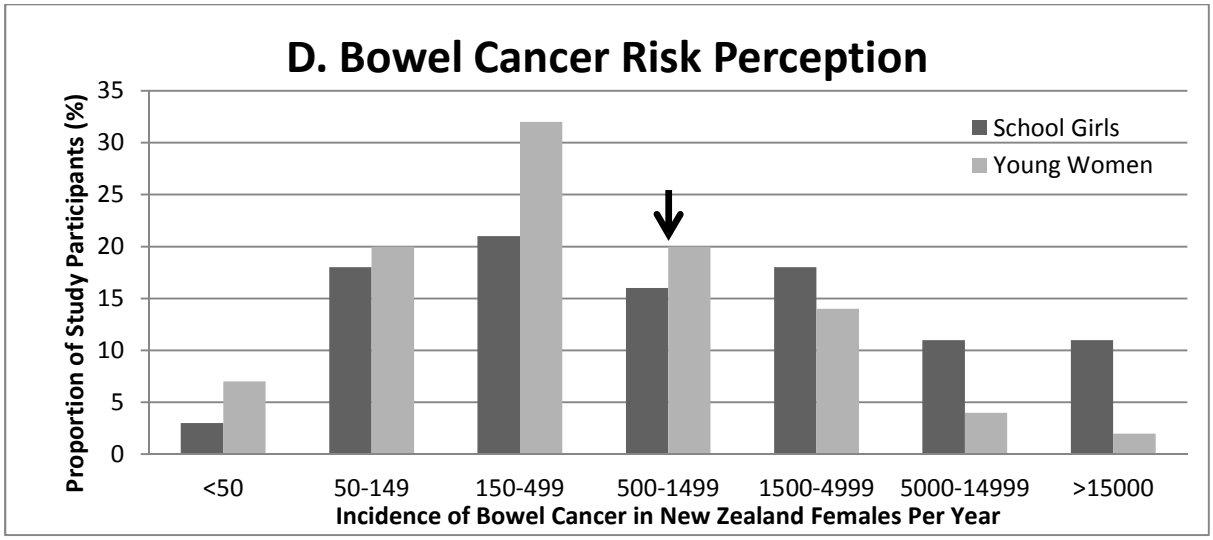
The four distributions for young women were different to a statistically significant level ($p < 0.001$), as were the four distributions for school girls ($p = 0.022$).

Figure 2: Study participants' estimates of cancer incidences (arrows indicate correct answers)





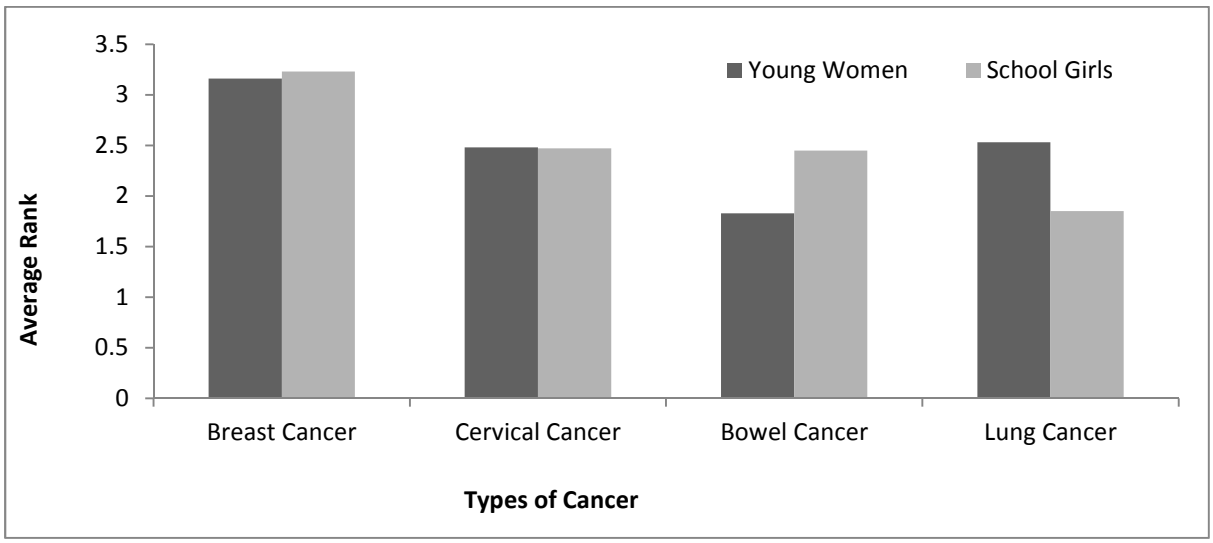




Ranks ascribed to each cancer are presented in figure 3. A higher rank indicates a higher perceived incidence: an average rank of 4 would imply all participants ranked that cancer as more common than the other three, while an average rank of 1 would imply all participants ranked that cancer as less common than the other three.

In the 23 to 28 year old group the results were; breast cancer: 3.16, lung cancer: 2.53, cervical cancer: 2.48, bowel cancer: 1.83. This was statistically significantly different from the null of 2.5 for all cancers ($p < 0.001$). The school group results were; breast cancer: 3.23, cervical cancer: 2.47, bowel cancer: 2.45, lung cancer: 1.85. This was similarly statistically significant ($p < 0.001$).

Figure 3: The cancer ranking scores for the school girls and young women.



Discussion

Our results show marked distortion in knowledge of cancer risk amongst our participants. The risk of cervical cancer was overestimated by both the school aged girls and the young women, while other cancers were underestimated. Cervical cancer incidence was falsely ranked higher by both groups. The most common age for risk of cancer was incorrectly thought to be in middle aged women by both groups.

A high proportion of both groups thought that the HPV vaccine prevents cervical cancer (100% of school girls and 98% of young women). This is comparable to the studies done in America (10-12), which showed approximately 80% or more of the participants thought that HPV is associated with cervical cancer. However, a lower proportion of both groups thought that HPV vaccine prevents genital warts (10% of school girls and 27% of young women), consistent with previous studies (10-14). We suspect that this may be due to the way Gardasil ('cervical cancer vaccine' (8)) is marketed, placing greater emphasis on the association of HPV with cervical cancer.

Members of the school aged group were more likely to be exposed to the vaccine and associated marketing. A higher proportion of this group received the vaccine (compared to the young women) and these girls were more likely to report being satisfied with the amount of information they had received about it. While no differences were found between the groups in distortion of knowledge in regards to cancer risk and the association between HPV and cervical cancer, young women were more aware of the association between HPV and genital warts and the need for cervical cancer screening. We believe this may be attributed to a combination of greater knowledge and exposure to cervical cancer screening amongst young women. Young women were likely to be more educated than the school girls because they had probably completed high school. The cervical screening campaign was likely to have had greater influence on the young women as the recommended age to start screening in New Zealand is 20 (1) and no school girl met this age.

Study Limitations

The main limitation of this study was the low number of participants, which limited the statistical power of the study and is likely to have introduced selection bias. School girls were mainly from a high decile school and young women were predominantly from a local university, suggesting our sample population was likely to have greater education and wealth than the general population. So the results regarding knowledge and perceived cancer risk may have been falsely over stated. Despite this potential effect, we found marked distortion in knowledge of cancer risk perception.

Factors contributing to our low response rate include the limited time frame of the overall study (5 weeks), the reluctance of schools to participate due to the proximity of school exams, and the barriers of gaining parental consent for participation where the girl was younger than 16. One decile 4 school class did not consent to participate as the girls thought the survey was 'shameful', perhaps suggesting there were prior negative attitudes towards the study, which may have also contributed to selection bias.

Another limitation relates to the perceived cancer incidences. For these questions participants were asked to choose from a number of possible ranges, and the distribution of answers tended to cluster around the middle values. It is possible that where respondents did not know the answer they may have been more likely to choose the middle option, which may have introduced bias. In particular, this 'middle effect' would have contributed to the apparent over-estimation of cervical cancer risk, given that this cancer had the lowest actual incidence. However, this is mitigated by our alternative analysis looking at how participants ranked the cancers, which provided evidence for an overestimation of cervical cancer risk and was independent of this bias. Furthermore, there was statistically significant difference between the distributions of cancers ($p < 0.001$).

Study Strengths

The ethnic similarities between both groups facilitated their comparison (Table 2). The difference between the school girls and young women as highlighted by the survey questions in table 3 provides support for the use of appropriate age groups in regards to exposure to HPV vaccine and the associated campaign. Furthermore, the use of people that were not directly involved in the project to hand out surveys to school girls and the use of online survey for young women limited influence from investigators on participants' answering of the survey.

Despite the study's inability to demonstrate a statistically significant difference in the over estimation of cervical cancer risk and in the incorrect identification of the most common age to get cancer, between the exposed and unexposed group to Gardasil® and its associated media campaign, previous studies have suggested that cervical cancer risk perception is influenced by media and promotional campaigns (11, 13, 14, 15). We think the inability of the study to find a difference in cancer risk may be attributable to the cervical screening programme, which has been present from the 1990 (1), and its associated media campaign, which may be responsible for overstating the risk of cervical cancer and skewing the risk of any cancer to be more prevalent in middle aged women.

Our findings concerning cancer risk perception in school girls and young women have two main implications. One is the potential that other, more prevalent cancers and their signs may be down prioritised because people lack awareness and knowledge in these areas

compared to cervical cancer. An increased risk perception of cervical cancer may contribute to this as women are more focused on these signs as opposed to those of other cancers. Another implication is related to the ethics of informed consent. By overselling the risk of cervical cancer there is a risk that perhaps women are not receiving the correct amount of information to truly make an informed decision regarding cervical cancer screening.

Conclusions

The risk of cervical cancer was overestimated and the most common age for all cancers was falsely identified as the middle age group by both school girls and young women in Wellington. Although this study was unable to determine whether this distortion in risk perception was a result of the Gardasil® vaccine and its associated media campaigns, we believe this to be a contributing factor. There is room for exploration into this matter in future studies.

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