"It's Your Body But…"

Young Women's Narratives of Declining Human Papillomavirus (HPV) Vaccination

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Dans ce texte, les auteures relient la vaccination HPV (papillomavirus humain) à un processus socio-politique élargi qui veut médicaliser et pathologiser la sexualité féminine. Deux jeunes femmes qui ont refusé le vaccin nous racontent la lutte et les tensions qu'elles ont vécues quand elles ont affirmé leur position contre la vaccination.

In July 2006, Health Canada approved a vaccine called Gardasil™ for use in girls and young women aged 9 to 26. The vaccine aims to prevent against four strains of human papillomavirus (HPV), two of which have been associated with the development of genital warts, and two of which have been associated with the development of cervical cancer (Centers for Disease Control). Following the vaccine's approval by Health Canada, and with the assistance of federal funding, the Ontario government launched a voluntary school-based vaccination in program in 2007 for girls in grade eight (Torgerson and MacAdam). Currently, publicly funded HPV vaccination programs are available in all provinces and territories (Public Health Agency of Canada). Those who are not eligible for vaccination through school-based programs must purchase the vaccine at a cost of approximately $400- $450 if they wish to be vaccinated (Comeau 913).

Whereas the rationale for mass immunization during grade school derives from the recommendation to vaccinate before sexual onset, university-aged women, many of whom are already sexually active, have been heavily targeted by government and industry-sponsored media advertisements about HPVand Gardasil. The language and images used both in industry-sponsored advertisements and health information materials for HPV vaccination exhort young women to assume responsibility for their sexual health and to protect themselves from cervical cancer by "choosing" to vaccinate. While floor-to-ceiling print ads conspicuously wallpaper university corridors and call on young women to be "smart" " and "do all they can" to avoid getting cancer, television advertisements and pamphlets littered across university campuses, in sexual health clinics, and in doctors' offices, instruct young women to "spread the word" and "not the disease" (Polzer and Knabe 869). Such messages not only blur the line between public health education and the marketing of pharmaceutical products, but they also reinforce assumptions about the female body as a primary vector of sexually-transmitted infections and site of risk for future disease (cervical cancer). The pervasiveness of such messages sets up a moral landscape in which saying "no" to vaccination is interpreted, at best, as a sign of ignorance, and, at worst, as a sign of negligence to care for one's own health and the health of others (Polzer and Knabe 869).

Decision-Making, Risk and Neo-medicalization

To date, most studies on HPV decision-making have been quantitative in design and have thus relied on structured questionnaires or surveys that provide participants with a list of pre-determined options regarding what factors influence their decision-making. Furthermore, research on decision-making in the field of health education tends to assume an overly simplistic view of how people make decisions in the context of their everyday lives. Often, decision-making is framed as a linear process which involves individuals weighing the pros and cons to arrive at a final "rational" decision at a specific point in time. Indeed, in the context of HPV vaccination, decisions to vaccinate are framed as the smart and rational choice for young women. As a result, it is often assumed (and expected) that once women are provided with information about HPV and its link to cervical cancer, they will readily accept vaccination as the appropriate preventative action.

The concept of neomedicalization is useful to situate young women's decision making about HPV vaccination within the broader socio-political matrix. Batt and Lippman define “neomedicalization” as a form of medicalization which “emphasizes an individual’s supposed risk of developing a problem and the use of some drug or device to manage this risk. In its most expansive form, neomedicalization makes being ‘at-risk’ a disease state and frames the individual as responsible for ensuring that the risk does not become reality” (50). As Batt and Lippman point out, processes of neomedicalization are symptomatic of neo-liberal policies which construct health as a malleable commodity and basis for economic growth through the expansion of drug interventions aimed at managing risks to health (50-51) and place responsibility for risk management squarely on the shoulders of individuals and families who are expected to consume these drugs and devices. Processes of neomedicalization thus serve to individualize risks to health and to deflect attention from structural issues that determine health. In the context of HPV, these broader considerations include access to cervical cancer screening and the broader social determinants of health which render marginalized women (e.g. recent immigrants, Aboriginal women, women on low-income) particularly vulnerable to HPV and cervical cancer.

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By linking sexual activity with risks for acquiring HPV and HPV with the possibility of developing cervical cancer in the future, discourses on HPV vaccination represent a contemporary expression and extension of the pathologization of female sexuality and construct young women as appropriate targets for neomedicalization. With emphasis placed on individual responsibility and personal control over health, neoliberal discourses on health risk conveniently co-opt feminist challenges to medicalization that emphasize autonomy and taking charge of one’s heath.

Furthermore, individuals are increasingly framed by risk discourse as having a responsibility to preserve their health not only for their own benefit, but for the benefit of family members, and society as a whole (Peterson and Lupton 82). According to Petersen and Lupton, discourses of citizenship and personal responsibility are embodied in a particular way by women as neo-liberal subjects. As they describe, “the meanings associated with ‘health’ and ‘protective behaviours’ are inextricably linked with the feminised discourses of ‘looking after yourself’, risk avoidance and caution, and are highly embodied” (82). This has implications for young women who may feel compelled to perform their independence and exercise their responsibility to do the “right thing” by managing their risks for future cancer through vaccination. In the context of dominant discourses on health risk, and the media advertisements for HPV vaccination, as outlined above, some young women may find it difficult to adopt a critical perspective on the vaccine and to justify their decisions to postpone or decline vaccination altogether.

The Study

In order to learn more about how young women make decisions about HPV vaccination, a narrative study of young women’s decision-making concerning HPV vaccination was undertaken. As a unique approach to qualitative health research, narrative methodology was used as a way to gain insight into young women’s personal experiences for two reasons. First, the use of a narrative methodological approach provided participants the opportunity to define their experiences in their own ways rather than have their realities be shaped by structured data collection methods. Second, narrative allows us to learn about the ways in which narrators, through their personal stories, reproduce larger discourses and struggle with tensions in articulating their stories as they make sense of their experiences (Chase 651). Such tensions often point to the ways in which participants are challenging or resisting dominant discourses (Mishler 87).

In-depth interviews were conducted with five young women between the ages of 18 and 26, each of whom participated in two interviews. In the first interview, participants were asked to respond to the question: “In as much detail as possible, tell me your story of how you came to be/not be vaccinated against HPV.” The second interview was used as an opportunity to seek further detail on stories that were introduced in Interview 1. The analysis was conducted iteratively and in two general phases. During the first phase, narratives for each participant were constructed through the processes of “narrative creating” and “narrative finding” (Kvale 199). “Narrative finding” refers to looking for portions in the interviews that are essentially intact stories whereas “narrative creating” refers to weaving the un-storied aspects of the interviews into each participant’s narrative

(Kvale 199). During the second phase of analysis, the individual narratives were reviewed in order to develop cross-narrative themes.

Although attempts were made to obtain a diverse sample, all five study participants were students at the university where the study was conducted. Although this imposed limitations with regard to the demographic diversity of the study participants, the sample was diverse in terms of the decisions participants reached in relation to HPV vaccination: two of the women had accepted and had already been vaccinated, two of the women had declined vaccination, and one participant was undecided about vaccination at the time of recruitment.

In what follows, we focus on the individual narratives of the two study participants who declined vaccination, Ana and Kristin (pseudonyms), in order to illustrate the struggles and tensions that these young women experienced as they attempted to adopt critical positions in relation the vaccine. In contrast to the narratives of those participants who had been vaccinated, both of these young women's narratives were fraught with difficulties as they described and defended their decisions *not* to be vaccinated. In presenting these narratives, we raise questions and provoke critical reflection about what such cancer prevention discourses mean for young women's autonomy in health decision making.

Ana's Narrative

Ana's narrative was shaped by her strong personal ethic when it comes to taking medications and vaccines. Throughout both interviews, Ana described her strong personal ethic against putting "foreign" things into her body unless she knows "what's gonna happen afterwards." In discussing the HPV vaccine, Ana said she is "wary" of the possible long-term side effects of vaccination because there is too much "unknown." Ana used the example of the "drug that gave babies no arms" (Thalidomide) to show how an approved drug still turned out to be unsafe. Ultimately, Ana said that unless she is "100 percent sure" that the vaccine is something that will protect her health, she will just continue to "go for the cautious end of it and just not do it."

Of particular interest in Ana's narrative, is her struggle to align who she is with how she came to decline vaccination. For Ana, this struggle results in two competing ways of seeing herself. On the one hand she describes herself as "critical", "educated", and "cautious," while on the other hand, she describes herself as "lazy" and "passive." According to Ana, her ability to be critical and cautious "comes from six years of being in university" during which, in "almost every class", she was told that "it's all about critical thinking." Ana described her critical way of thinking as a "revelation" that came from her being a student in a "feminist based program" that has taught her a lot about "social issues and social justice."

Despite expressing confidence in her critical perspective, Ana simultaneously described herself as "lazy" and "passive." In this sense, Ana felt that her critique of the vaccine did not have a strong foundation since she had "never done any more research" or "sought out any opposing information". The fact that she hadn't sought out information about the vaccine led her to describe herself not just as "sceptical" but also as "ignorant." Ana described her failure to put in the "extra effort" and seek information as part of her usual "lazy way." In the second interview, Ana began to question her decision against vaccination and suggested that maybe it was "stupidity" on her part because she "should" be taking care of her body. By the end of the second interview, Ana acknowledged the tension between her two competing selves by outlining two distinct types of people. As she described, "you could be the really proactive type and really do that research and really be educated and you know, be a good person or you could be the person who just takes information as it's provided to them." For Ana, this distinction was an important one in that she described herself as someone in the "middle of the road."

Kristin's Narrative

Kristin began her narrative by listing the main reasons why she is "not really for" the vaccine. Within the first few minutes of her interview, Kristin had already listed at least four reasons why she chose not to be vaccinated. In addition to not seeing "the need for it" and viewing it as "just another tool" in addition to PAP smears, she also questioned "how effective the vaccine would be" since she has had "multiple sexual partners" and therefore has already likely "been exposed" to the virus.

Once she finished listing her reasons for not wanting to be vaccinated, Kristin went on to describe how she has had to defend her decision not to be vaccinated on a number of occasions with her friends, and how she has been labelled as "irrational" and "stubborn" by her boyfriend and others when she raises her concerns about the potential side effects of the vaccine. As Kristin described, one friend (who had gotten the vaccine) was "aghast" at her decision and asked why she wasn't getting the vaccine as well. Kristin responded by saying that she is "wary of pharmaceutical companies and wonder drugs" and that she is "not scared to wait five years just to see how it all pans out." Kristin also noted that her male friends have also offered their opinions by saying "it's your body, it's your decision, but why wouldn't you wanna' fight a cancer that you could?" According to Kristin, being "perceived" as "irrational or emotional" in her "decision making" is a "pet peeve" of hers. As she described, "it's a nerve that's picked with me because I know I'm very rational in all of my choices."

Kristin also emphasized her concern with her reproductive future in her narrative. In order to articulate her concerns regarding the safety of the vaccine, Kristin, like Ana, drew on the example of "Thalidomide" which she says "really resonates" with her. For Kristin, the HPV vaccine, like Thalidomide, may turn out to be "not-so-great" if it causes "more problems having children, or if there are side effects, difficulties, or problems with pregnancies" in the long term. She emphasized that, since no information is currently available regarding the potential side effects of the vaccine, she has decided that she is "willing to wait" to see if it has any effects on "fertility" in the long term.

Kristin's decision to decline vaccination is at odds with risk-related discourses and the moral imperative of taking action to reduce one's risk for disease, [and] she is thus called upon to defend her decision in order to avoid being labelled "irresponsible."

According to Kristin, she took it upon herself to become "informed" about the HPV vaccine because she felt it was her "responsibility" to do so. Despite seeing "commercials" about the vaccine, reading many "news stories," and visiting multiple "websites," she noted that the vaccine never really "perked" her interest because she "didn't see the need for it." For Kristin, its "role" as she saw it, was already being filled in her "health portfolio." As she described, "I think PAPs (Papanicolaou smears or tests) are sufficient because I'm on top of them and I do all my sexual health things."

Although Kristin described herself as responsible and aware of her "sexual health" options, she said she was "irritated" that her mom and sister were different from her in this way. As she described, they "won't take ownership of their own reproductive health" and "they don't do anything sexual health reproduction wise." Instead, Kristin said they just "bury their heads in the sand" when she tells them to "go get PAP smears."

According to Kristin, being "well versed" in sexual health matters is a "responsibility" that "comes along with the privilege of being sexually active." As she described, "I've always thought that sexual health is my responsibility and that I should know what's out there, know the consequences and the repercussions so that I do actually know the full gamut or the weight of the decisions I'm making."

Discussion

Ana and Kristin's narratives demonstrate that decisions regarding HPV vaccination result from processes that are complex and ongoing, and are inevitably located within, and influenced by, dominant discourses on health risk. Although Ana and Kristin were both critical of the HPV vaccine as a risk-reduction measure and concerned about its safety, the narratives of both of these young women show that they oriented their decisions in relation to dominant discourses on health risk which promote individual responsibility for health.

Ana's narrative highlights her struggle to define who she is in relation to her vaccination decision. Specifically, Ana struggles to make her decision not to seek vaccination or information about vaccination commensurate with moral discourses related to taking responsibility for one's own health. Ultimately, Ana's orientation as someone who is critical and cautious and her decision not to be vaccinated are at odds with risk discourse which promote the idea that she should do all she can, including vaccination, in order to reduce her risks for cervical cancer.

Indeed, the power of risk discourse in influencing Ana's view of herself is evidenced in how she feels compelled to question and judge herself for not seeking out information and becoming more informed about the vaccine. The discourse of morality which permeates notions of risk management and personal responsibility for health ultimately informed Ana's consideration that one of the reasons she hasn't sought information is because of her own "stupidity" since she "should" be taking care of her own body. Ultimately, although Ana is attempting to challenge the imperative to get vaccinated and question the ways in which HPV has come to be constructed as a risk, she struggles to do so in the face of prevailing discourses which frame the vaccine as the appropriate and responsible choice.

Like Ana, Kristin is also critical of the HPV vaccine and struggles to resist dominant discourses that position the vaccine as the ideal risk-reduction tool. Much of Kristin's narrative focuses on her experiences defending her decision to others, including those in her immediate social network. Whereas Ana judges herself for not seeking out information about vaccination, judgements from Kristin's friends arise from their understandings of HPV as a risk and vaccination as a means of controlling this risk through medical intervention. Because Kristin's decision to decline vaccination is at odds with risk-related discourses and the moral imperative of taking action to reduce one's risk for disease, she is thus called upon to defend her decision in order to avoid being labelled "irresponsible."

In order to construct herself as a responsible risk manager in light of her refusal of HPV vaccination, Kristin describes herself as someone who, through yearly PAP tests, does everything she can to remain "aware" of her body and "what's going on with it." To this end, and in distinction from Ana, Kristin describes how she took it upon herself to become informed about HPV since she felt it was her "responsibility" to do so.

Conclusion

The narratives of these young women illustrate that decision-making about HPV vaccination is complex and influenced by the broader social and political contexts in which dominant discourses on health risk circulate and operate. In their narratives, both Ana and Kristin draw on ideas about personal responsibility for health in their descriptions of themselves as people who, despite their decisions not to be vaccinated, manage their risks for cervical cancer in other ways (e.g. through regular Pap screening). Ana struggles to reconcile her failure to seek out information about the vaccine and her decision not to be vaccinated with moral discourses of assuming personal responsibility for health through risk management. In contrast, Kristin struggles to defend her refusal of the vaccine within her immediate social network, yet remains confident in her construction of herself as a responsible risk manager through taking up the imperative to become informed about the vaccine and reconciling her refusal of the vaccine with her desire to protect and take responsibility for her reproductive health.

By showing how young women struggle to resist dominant discourses related to health risk and personal responsibility for health, this research makes a significant contribution to understanding how processes of neo-medicalization have come to construct HPV as a risk to women's health and vaccination against HPV as a solution to managing this risk. As demonstrated in the narratives of Ana and Kristin, young women are responding to an implicit moral obligation to take up vaccination in order to construct themselves as responsible managers of their risks for cervical cancer. These findings raise critical questions about what such cancer prevention discourses mean for young women's autonomy in health decision making in the context of neomedicalization.

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References

Batt, Sharon. and Lippman, Abby. "Chapter 3. Preventing Disease: Are Pills the Answer?" *The Push to Prescribe: Women and Canadian Drug Policy.* Ed. Anne Rochon Ford and Diane Saibil. Toronto: Women's Press, 2009. 47-66.

Canada. Public Health Agency of Canada. Publicly funded Immunization Programs in Canada - Routine Schedule for Infants and Children (including special programs and catch-up programs). Ottawa: 2010. Web. <http://www.phac-aspc.gc.ca/im/ptimprog-progimpt/table-1-eng.php>.

Centers for Disease Control and Prevention (CDC). *HPV Vaccine Information for Young Women.* 2008. Web. 13 Feb. 2010 <http://www.cdc.gov/std/hpv/STDFact-HPV-vaccine-young-women.htm>.

Chase, Susan E. "Talking Narrative Seriously: Consequences for Method and Theory in Interview Studies." *Turning Points in Qualitative Research: Tying Knots in a Hankerchief.* Ed. Yvonna S. Lincoln and Norman. K. Denzin. Walnut Creek, CA: AltaMira Press, 2003.

Comeau, Pauline. "Debate Begins Over Public Funding for HPV Vaccine." *Canadian Medical Association Journal* 176.7 (2007): 913-914. SCOPUS. 18 October 2010.

Kvale, Steinar. *InterViews: An Introduction to Qualitative Research Interviewing.* Thousand Oaks, CA: Sage Publications, 1996.

Mishler, Elliot. G. "Models of Narrative Analysis: A Typology." *Journal of Narrative and Life History* 5.2 (1995): 87-123. SCOPUS. 20 October 2010.

Petersen, Alan and Lupton, Deborah. *The New Public Health: Health and Self in the Age of Risk.* London; Thousand Oaks, CA: Sage Publications, 1996.

Polzer, Jessica and Knabe, Susan. "Good Girls do … Get Vaccinated: HPV, Mass Marketing and Moral Dilemmas for Sexually Active Young Women." *Journal of Epidemiology and Community Health* 63.11 (2009): 869-70. SCOPUS. 6 November 2010.

Torgerson, Renee and MacAdam, Margaret. "HPV Vaccine Funded in Canada." *Health Policy Monitor* 2007. Web. 15 Apr. 2010 <http://www.hpm.org/survey/ca/b10/2>.