“IT'S YOUR BODY BUT...”:
POLITICIZING YOUNG WOMEN'S PERSONAL NARRATIVES OF HPV VACCINE DECISION MAKING USING CRITICAL NARRATIVE METHODOLOGY

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Presentation Outline

- Locating the research
- Critical Narrative Methodology
- Insights re: Risk and Subjectivity
- Implications for Theoretical Development
Critical Orientation

How does our technological and pharmaceutical landscape of “risk management” shape:

- how we think about risk?
- how we manage risks?
- how we define particular bodies and persons as risky (and others not)?
- how we think and act upon ourselves and others as subjects and objects of risk?
Proliferation of Discourse on HPV
HPV stories in the news

- HPV as disease among youth (“epidemic” of HPV)
- Comparisons with other STIs to establish HPV as serious health risk
  
  *despite its deadly potential, [HPV] has never had the big-time profile afforded to other STDs. Chlamydia and herpes have had their names in lights, but HPV - often misunderstood as merely warts... lurks in the shadows TO Star, March 7, 2003*

- HPV as common but potentially deadly
- Condoms can’t protect you (but vaccination can)

HPV stories in the classroom

- Stories from students and colleagues suggest, for example:
  - unresponsiveness of physicians to young women’s requests for information
  - difficult situations and conversations between family members (particularly mothers and daughters)
HPV Vaccine (HPVV) Promotional Materials
Biological Risks or Gendered Responsibilities?

- HPV constructed as a risk through the body of the innocent girl and her impending sexuality
- Construction of the “universal girl at risk”
- Sets into motion a set of responsibilities to manage risks, particularly for mothers and young women
HPV in Canada

- HPV is most common STI worldwide; highest rates b/w 15 and 24 yrs; infections are transient and most cases clear spontaneously

- Persistent infection with high risk HPV types linked to genital warts, cervical cancer, and cancers of the penis, vulva, vagina, anus, head and neck

- Differences observed in vulnerability to HPV-related cancers follow gradient

- HPV vaccination (HPVV) first approved for females (2006), then males (2010); School-based programs in all provinces and territories for females aged 9-13
Research on decision-making

- Tends to focus on knowledge, awareness, intentions; neglects how individuals *actually* understand their risks and make decisions about vaccination

- Overwhelmingly quantitative; obscures social contexts of decision-making

- Most research with heterosexual women; limited research with LGBTQ participants; little consideration of how notions of gender and sexuality intersect with and shaped by HPV discourse
# Contrasting Approaches to Risk

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<thead>
<tr>
<th></th>
<th><strong>Technico-Scientific</strong></th>
<th><strong>Socio-cultural</strong></th>
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<tbody>
<tr>
<td><strong>Ontological Characterization</strong></td>
<td>Risks exist independently of broader socio-political contexts</td>
<td>Risks constituted by and emerge within particular socio-political contexts</td>
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<td><strong>Epistemological Positions</strong></td>
<td>Representations of risk reflect reality</td>
<td>Representations of risk construct reality</td>
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<tr>
<td><strong>Methodological Approach</strong></td>
<td>Risks are quantifiable as scientific probabilities and measured using structured surveys</td>
<td>Meanings ascribed to risk constructions elucidated through inductive qualitative approaches and methods</td>
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<td><strong>Goal of Research</strong></td>
<td>To predict, manage and control risk</td>
<td>To understand and challenge dominant socio-political constructions and their effects</td>
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Health promotion and discourses on health risk:

- produce “at risk” self; construct the self as an enterprise which engages in processes of self-reflection and self-improvement as part of their “duty to be well”

- Emphasize individual responsibility to manage health risks prior to the onset of symptoms; deflect attention from social determinants of health
Neo-Medicalization

“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.” Batt & Lippman, 2009 p.50)

- co-opts and capitalizes on feminist challenges to medicalization
The medicalization of agency

How do young women aged 18 to 26 convey their experience of making decisions about HPV vaccination in the context of their daily lives?”

The objectives were to:

- identify the meanings that young women ascribe to HPVV;
- identify and explore influences on vaccination decisions;
- identify and explore challenges and/or tensions that young women encounter in making decisions about HPVV;
- situate these meanings, influences and challenges in relation to broader discourses.
Distinct approach to qualitative research with no single heritage

Key assumption > stories are a key resource and means through which people give meaning to their experiences and lives

gives participants opportunities to narrate experiences in their own ways; gives researchers insights into the ways in which narrators reproduce/resist discourses
Constructivist Narrative Approach

- Key tenets of constructivist approach

- Narratives viewed as co-constructions produced by narrator (research participant) and listener (researcher), produced at a specific time and place and for a specific purpose

- Researcher not interested in pursuing a single “truth”
Reflexivity

- Acknowledges role of research in co-constructing narratives

- Strategies:
  - Reflexive statement written early on in research process
  - Continuous journaling
  - Discussions with thesis supervisor and advisory committee
Story vs. Narrative

- narratives necessarily involve stories; a person’s narrative is made up of more than a single story- it is a collection of stories

- story > refers to individual accounts of events and/or experiences as narrated by participants

- narrative > refers to the co-constructed organization of stories into a coherent whole
# Sample

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Demographic Information</th>
<th>Vaccination Status</th>
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</thead>
<tbody>
<tr>
<td>Allison</td>
<td>19 yrs, Undergraduate Student&lt;br&gt;Not sexually active</td>
<td>Considering Vaccination</td>
</tr>
<tr>
<td>Katie</td>
<td>19 yrs, Undergraduate Student&lt;br&gt;Sexually Active</td>
<td>Vaccinated</td>
</tr>
<tr>
<td>Paige</td>
<td>22 yrs, Undergraduate Student&lt;br&gt;Sexually Active</td>
<td>Vaccinated</td>
</tr>
<tr>
<td>Ana</td>
<td>25 yrs, Graduate Student&lt;br&gt;Sexually Active</td>
<td>Not Vaccinated</td>
</tr>
<tr>
<td>Kristin</td>
<td>24 yrs, Graduate Student&lt;br&gt;Sexually Active</td>
<td>Not Vaccinated</td>
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Interview 1

- 2 part interviewing strategy (Bertaux & Kohli, 1984):
  1. extensive narration; 2. active engagement

- Interview 1 – “Can you, in as much detail as possible, tell me your story of how you came to be (or not be) vaccinated against HPV? Feel free to start wherever you want and end wherever you want- it’s completely up to you.”
  - Consciously avoided framing prompt using “decision”

- Interview 1 transcribed and shared with participants who were asked to review them before interview 2
Interview 2

- Personalized semi-structured interview guide developed from interview 1 to guide interview 2

- Interview 2 – Began by soliciting feedback on review of Interview 1, then detail sought on themes introduced in Interview 1 using personalized semi-structured interview guide, e.g.:
  - You mentioned ___ when we last talked, can you tell me more about that?”
Field Notes

- Unstructured notes written after each interview included:
  - dynamics of the conversation
  - dominant phrases used by participants
  - new or repeating ideas
  - contextual factors (e.g. time, location, setting, moods, body language)
  - concepts or ideas that seemed central
  - concepts or ideas that needed further exploration
  - researcher’s ideas, hunches, questions
  - ideas for questions for interview 2

- Writing field notes used to document analytic process and emergent themes and remain attuned to how researcher was influenced by the data (Marshall & Rossman, 2006).
Analysis

- 2 phases:
  1. Development of individual narratives for each participant
     - Narrative themes generated for each participant
  2. Cross-narrative analysis
     - Individual narratives compared to generate cross-narrative themes
1. Constructing the Narratives

- Identified key themes from both interviews for each participant
- Questions used to engage systematically with the data:
  - What and/or who was talked about?
  - How did participants begin and end the interview?
  - How did each young woman talk about vaccination?
  - Who or what did participants identify as influences in their decision making?
  - How did participants talk about themselves in relation to the vaccine and/or their decision?
  - Were there any tensions or ambivalences in their stories? How, if at all, did they resolve these tensions?
  - How did their stories evolve/change between the interviews?
1. Constructing the Narratives

- Narrative Finding and Narrative Creating (Kvale, 1996)
  - **Finding** > portions in the interviews that are essentially intact stories
    - e.g. “Katie found out about the vaccine from her mother, who was a physician”
  - **Creating** > weaving un-storied aspects of the interviews into the narrative
    - e.g. Ana’s “struggle to claim authority” emerged through various references to ambivalence and uncertainty
2. Cross-Narrative Analysis

- **Thematic Component** - Individual participant narratives compared through multiple close readings in order to identify cross-narrative themes

- **Discursive Component** - Participant narratives interpreted in light of wider discourses (e.g. on risk, medicalization, and individual responsibility for health)

- Development of cross-narrative themes is iterative, not linear
Quality Criteria

- **Width** - ensuring comprehensiveness of evidence
  - Lieblich et.al (1998)

- **Coherence** – how the parts fit together
  - Lieblich et.al (1998)

- **Trustworthiness** – documenting analytic process
  - Mishler (1990)

- **Wakefulness** – remaining aware of interpretations and alternatives
  - Clandinin (2000)
Presenting the Narratives

3 components to each participant’s narrative:

1. **Summary of demographic information** (e.g. “Katie is a 19 year old woman...”)

2. **Researcher’s Reflections** (e.g. “From the first to the second interviews, I noticed that Katie went from talking about the vaccine as something routine and necessary, to something that she may not have needed after all.”)

3. **Narrative Themes**
Narrative Themes - undecided

- Allison, 19
  - (Not) Knowing About HPV or the Vaccine
  - Waiting for a Reason
  - Finding Information
  - Re-thinking Vaccination
Narrative Themes - vaccinated

- **Katie, 19**
  - Listening to Dr. Mom
  - Reacting to the c-word
  - Spreading the word to friends

- **Paige, 22**
  - Maintaining silence about sex
  - Overcoming communication barrier
  - Better safe than sorry
Narrative Themes – not vaccinated

- Kristin, 24
  - Weighing the risks & benefits of vaccination
  - Defending her decision to decline

- Ana, 25
  - Trust in screening
  - Not putting foreign things into her body
  - Struggling to claim authority
Katie began her first interview by saying that her parents are doctors ... basically I follow their advice. Katie’s mother told her you have to get this...

The commercials ... led her to believe that there was this big outbreak of cervical cancer [...] I thought that meant we were at-risk.

Part of the reason she agreed to get the vaccine was because it was associated with the word ‘cancer’. As she put it, I’ve had a lot of people in my family have cancer... I don’t want cancer

Katie’s story centred on her ability to spread the word to her friends.

Katie felt that the protection that came with vaccinating would never have to come into play because she would never get an STD which she described as kind of like a mythical thing!
Kristen – Protecting reproductive health by declining vaccination

Kristen questioned the need for it and how effective it would be because she had already had multiple sexual partners and had been exposed.

Kristen recounted how she had to defend her decision not to be vaccinated with her boyfriend and friends who labeled her as irrational, stubborn and a pessimist. One female friend was aghast at Kristen’s decision and male friends questioned her saying it’s your body, it’s your decision but why wouldn’t you wanna’ fight a cancer that you could?

In contrast, Kristen prided herself on being really on top of and well versed in her sexual health which she viewed as a responsibility that comes along with the privilege of being sexually active.

Kristen didn’t see the need for the vaccine because this was already filled in her health portfolio by going for regular Pap smears.
Ana didn’t have a lot of pull towards the vaccine when she first saw it advertised on TV. HPV was not a pressing issue for her.

She noted that genital warts and cervical cancer are horrible things yet she did not think of herself as very high risk because she is pretty adamant about getting physicals.

Throughout both interviews, Ana described her strong personal ethic of not putting foreign things into her body unless she knows what’s gonna happen afterwards.

Ana’s struggled to claim authority over her opinions regarding the vaccine. This struggle resulted in describing herself in two ways; on one hand, she described herself as critical, educated, and cautious while on the other hand, she described herself as lazy, ignorant and passive.
The challenge of declining vaccination: Doing the right thing?

By the end of the second interview, Ana began to acknowledge the tension in her narrative - a realization which led her to identify two competing selves; 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 moral distinction was an important one in that she described herself as someone in the “middle of the road.”
Cross-Narrative Themes

- Fluidity and temporality in decision-making
  - Decision-making neither static nor linear; characterized by ambivalence and tension

- Multiple Influences and Interpretations of Risk
  - Decisions actively negotiated through multiple relationships

- The Construction of Subjectivity through Decision-Making
Young women construct themselves as particular kinds of persons through their HPV vaccine decisions:

- **Katie** – vaccinated by “Dr. Mom”; constructs herself as the good daughter, the compliant patient and the caring friend (responsibility to “spread the word”)

- **Kristen** – refused vaccination through engaged reflection and as part of her responsibility for sexual health; vigilantly defended her decision with friends

- **Ana** – came to question her critical stance and her decision to say no to vaccination and left uncertain about what the right thing is to do
Narratives not only give us insight into personal experience, they also allow us to learn about the ways in which narrators reproduce broader discourses as they make sense of their experiences and themselves (Chase 2003).

Thus, the unique decision making experiences of Katie, Ana, and Kristin, are also stories about the discursive contexts that influence how these young women understand themselves and construct their subjectivities in relation to risk discourse and their vaccination decisions.
Conclusions

- Narrative methodology provides insight into:
  - the complex and relational nature of decision-making and subjectivity formation related to risk
  - how young women respond to, reproduce, negotiate and attempt to resist dominant discourses on risk and imperatives to vaccinate
  - how young women actively participate in processes of neo-medicalization in ways that do not conform to theoretical expectation
Questions

- Narrative methodology poses questions for and challenges theoretical notions of the entrepreneurial subject

  - Decision to decline vaccination ≠ rejection of entrepreneurial stance

  - Decision to accept vaccination ≠ assumption of entrepreneurial stance
Thank you!

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